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3 Counties IMCA Service – Written evidence

Overview and context

To what extent has the Mental Capacity Act 2005 (MCA) achieved its aims?

In our experience, implementation of the Act has been patchy and of different character in different localities. At its best, the Act can lead to greatly improved outcomes for a person, and improve the confidence and competence of professionals. At its worst, it can be interpreted as a means for professionals to get people to do ‘what the professional thinks is right’ or to do what has already been decided on without reference to the person’s wishes or feelings, or those of family.

Which areas of the Act, if any, require amendment; and how?

We feel that there is need for regulation or ‘comeback’ in relation to the operation of the Act. Wronged individuals could follow local complaints processes, or alternatively in serious cases take it to the Courts for judicial review (practically very difficult to do however). But there is otherwise no clear pathway for collecting information about trends or patterns, and no regulation of the Act. So for example in the areas of assessment of capacity, best interests decision-making and the reasons for decisions, whether an IMCA has been appointed, how consultation happened, there is no generally available data about how authorities are performing, or whether people are making complaints or raising issues about practice.

At times, it seems that access to advocacy support and representation is too limited by the way that the Act limits the access to IMCA. Frequently IMCA would be of use to people who have family or friends. The quality of ‘consultation’ with family or friends can be vary varied, and is often limited to informing or giving only partial information. An experienced advocate is able to ask questions and challenge professionals where an ordinary friend or family member is unlikely to have the confidence, skills or tenacity to be able to do so.

At the core of the MCA are its principles and definitions of capacity and best interests. Are these appropriate?

These principles and definitions can be a useful way of going back to solid ground when decisions become difficult or are contested.

Implementation

To what extent have the five principles of the MCA been implemented in frontline practice? What evidence is available to assess this? Is there a satisfactory balance between enablement and protection?

How effective was the Government’s implementation plan? What measures were taken to ensure that professionals and families of those who lack capacity know about and act in accordance with the provisions of the MCA? Has it led to sustainable change?

The implementation has been patchy. This may be because the basic approach of the Act is at odds with very widespread paternalistic and risk averse approaches amongst health and social care practitioners.

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Is the Act widely known and understood by professionals required to implement it? How does this differ across different sectors, such as health, social care, banking and others?

Is the Act widely known and understood by those who are directly affected by it and by their non-professional carers? To what extent does the Act provide protection and reassurance for informal carers? Has the right balance between struck between protection of the carer and protection of the individual lacking capacity?

In our experience, the Act is not widely known or understood amongst service-users and carers.

Has the Act ushered in the expected, or any, change in the culture of care?

Is there any evidence that the provisions of the MCA affect some groups disproportionately? If so, what data exists to compare representation across different socio-economic groups, Black and Minority Ethnic groups, and gender?

Decision making

Are those directly affected by the Act being enabled and supported to make decisions for themselves to a greater or lesser extent than they would have been in the past? Does the means by which the decision is made – ‘general authority’, Lasting Power of Attorney, deputyship, Court of Protection – affect the quality of decision making?

We think that the Act does enable and support people to make decisions or be part of decisions better than would previously have been the case. There are, however, outstanding areas. IMCAs pick up on the fact that decisions of medics are frequently taken unilaterally (i.e. missing out on the requirement of consultation), and would not conform to the best interests ‘checklist’. Also, the decisions of attorneys and deputies do not always appear to be as safe as other decisions.

What evidence is there that advance decisions to refuse treatment are being made and followed?

Has the MCA fostered appropriate involvement of carers and families in decision-making?

Has the role of the Independent Mental Capacity Advocate (IMCA) succeeded in providing a voice for clients and an additional safeguard against abuse and exploitation for those who have no-one to speak on their behalf?

We think that the IMCA role can be very valuable, and that the IMCA does frequently succeed in helping people’s voices to be heard in the general din. However, IMCA service providers cannot act alone. We depend on receiving appropriate referrals and information from a trained and aware health and social care workforce (and there seems to be no comeback for practitioners who fail to refer). Also, as a service provider we do struggle in with finding ways to channel concerns that we have about professional practice or about implementation of the Act.

Another key issue is that our independence is compromised by the nature of the IMCA commissioning process. Our service is commissioned by our Health Board. Although we are assured that lines are drawn within the Health Board between the operational and

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commissioning sides, it is very clear to us that there are operational workers involved in the monitoring and commissioning of our service, and this does not sit at all comfortably. We feel that this is an area of considerable importance that warrants further examination and consideration by central government.

Has the level of referrals to IMCAs met expectations? What are the reasons for the regional variations in the number of referrals?

Referral levels have very gradually climbed, but have not met expectations. We think that this is not due to variations in population, but rather in professional practice. We would link higher referral rates with knowledge (and willingness) of relevant professionals. It may be worth considering in light of this whether changes are needed to the referral process. I.e. is IMCA flawed as a safeguard because access to the service depends on the decision-makers?

Are IMCAs adequately resourced and skilled to assist in supported or substituted decision making for people lacking capacity?

Our IMCAs are very highly skilled and trained for the role and are very experienced.

The resourcing of the service is adequate at present referral levels (but bearing in mind that referral levels are lower than they ought to be, particularly in relation to ‘serious medical treatment’ and ‘adult safeguarding’). We have recently been asked questions about ‘value for money’ by our commissioners. Knowing that the money for IMCA commissioning has lost its ‘ring fenced’ status, what we fear is that there may be strong pressures for service commissioners to commission a cheaper service. We are concerned that we may move over to a position where the IMCAs are generally paid less, and the people who need an IMCA will lose out in quality of service received (i.e. experience and skills will be lost from the sector).

**Deprivation of Liberty Safeguards**

Are the safeguards in the Deprivation of Liberty Safeguards (DoLS) adequate?

There have been and continue to be significant problems around implementation of DoLS processes. Adequate systems are in place in many of the ‘supervisory body’ organisations, but not all.

Leaving aside the issue of implementation however, in our view, amendments are needed to this legislation. It is badly written and difficult to read or understand. The processes that are laid out are extremely bureaucratic and obscure, and don’t tie in well with actual practice in a health or social care setting. The experience for the person and his or her family can be one of difficulty in understanding what is happening, further alienation, and frequently add to the distress in an already distressing situation. Although it has helped to focus the minds of professionals on the issue, we suspect that the experience for professionals can often be bewilderment, discord, and stress.

One of the main problems is that the responsibilities for different elements of the safeguards in the DoLS are spread between a variety of people / organisations who are in practice unaware of this or unable or unwilling to fulfil those responsibilities. So, for example, the ‘relevant person’s representative’ role is absolutely key, but there is no surety that the person undertaking that role is able to do so, or that if he or she were not, that this would be picked up on.

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And again, it feels very much like there is no regulation or oversight of the processes. For example, often there are considerable delays (e.g. of many months) before a representative is even appointed. Or, frequently an IMCA will ask the supervisory body to be appointed under the s.39D role, having discovered that a person is not really represented. The risk though is that in most cases the IMCA will not come across the person, and even where the IMCA does make such a request, he or she may be turned down or ignored.

Are the processes for authorisation, review and challenge of DoLS sufficiently clear, accessible and timely?

There is a real danger with the DoLS, which is that it is often seen as a need for authorities to set up paperwork processes to make restrictions on a person 'legal', rather than being seen as making provision for actual and real safeguards for people in that situation. This means that once a person is under that system, it is still very hard for his or her voice to be heard, or for the person to challenge the restrictions, or for there to be movement towards better and less restrictive solutions.

The 'urgent authorisation' process has some problems. Because of the very short timescales, the effect of the Urgent DoLS seems to be to make the assessment process less fair for the person (rather than giving quicker access to fair processes for him or her). For example, IMCA instructions in those cases often come in so late that it is difficult for there to be really meaningful IMCA representation.

**The Court of Protection and the Office of the Public Guardian**

Are the Court of Protection and the Office of the Public Guardian sufficiently understood and accessible to all? Are they operating effectively and successfully?

In our view, access to justice is a huge issue – incapacitated people really do not seem to have proper access to justice.

What has been the impact of the introduction of Lasting Powers of Attorney (LPA), especially with regard to decision making on matters of personal care and welfare?

What concerns, if any, are there regarding the costs associated with registering an LPA, or with making an application to the Court of Protection?

Is legal aid available and sufficient? What impact will the recent and proposed reforms to legal aid have?

One of our IMCAs is acting as litigation friend to a person detained under DoLS in a care home. Following discussions about the right care regime and restrictions imposed on the person, the local authority agreed to take the matter to the Court to rule on DoLS. It was surprising that there was a means test for the person to have legal representation. Bearing in mind that this is a detained person who lacks capacity, one would have thought that he ought to have been entitled to automatic legal aid. If, for example, he had been detained under the Mental Health Act, and had the matter brought to Mental Health Review Tribunal by the hospital managers, or if he had brought the case to Court himself, he would have been entitled to non-means tested aid.

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In cases where a person lacks capacity and is not detained, the situation as regards costs and the availability of legal aid is not clear and seems less than desirable, even though the person may face very significant interference in his or her rights (especially right to private and family life).

**Regulation**

Is the role of the Care Quality Commission in inspecting on the MCA standards adequate and appropriate? Is there a case for additional powers?

In our view, more effective regulation of the Mental Capacity Act is needed. Professionals get away with poor or unlawful practice all the time and without having to acknowledge that this is the case or take any action to remedy this.

Should other regulatory bodies, such as health and social care professional regulators, be acting in this area?

**Other legislation**

How well is the relationship with the mental health system and legislation understood in practice?

**Devolved administrations and international context**

Does the implementation of the Mental Capacity Act differ significantly in Wales?

What lessons, if any, can be learnt from the approaches taken to mental capacity legislation in Scotland and Northern Ireland, or in other jurisdictions?

Is the MCA compliant with the United Nations Convention on the Rights of Persons with Disability (CRPD)? Are there lessons that can be learnt from the CRPD for the successful implementation of the MCA?

30 August 2013
Dr Julian Abel and Dr Nick Cartmell – Written evidence

From:
Dr Julian Abel, Consultant in Palliative Care, Weston Area Health Trust and Weston Hospicecare, and Dr Nick Cartmell, GP and Associate Director at the Strategic Clinical Network (Mental health, Dementia & Neurological Conditions) South West.

Background

Dr Abel was the Clinical Lead for End of Life Care for the South West Strategic Health Authority between 2008 and 2013 and in this role led the implementation of the National End of Life Strategy 2008 across the whole of the South West. This implementation focused in particular on advance care planning as an integral part of improving care for people who are in the last part of their lives. He continues to lead a network of End of Life care professionals in the South West.

Dr Cartmell was GP lead for Dementia for the South West Strategic Health Authority and continues to advise on improving services and support for people with dementia and their families and carers from diagnosis to end of life through his new role with the Strategic Health Authority and a similar role with South Devon & Torbay Clinical Commissioning Group.

Positive effects of the MCA 2005

The MCA has been a great help by:

- supporting the whole process of advance care planning;
- providing clarity around advance directives and advance decisions to refuse treatment;
- requiring that the opinion of family and carers is taken into account when making best interest decisions.

This has meant that we have been able to support people in developing end of life care plans, talk to health and social care professionals about what this means, and be clear on the legal basis for end of life planning.

Remaining problems with the MCA 2005

Despite the Act, however, significant problems still remain in practice:

1. **Professional knowledge** of the details of the MCA 2005 remains quite poor for many health and social care workers. Sometimes this manifests as over cautiousness and lack of trust in decisions that patients have made.

2. **Public understanding** of the MCA remains poor. Most people do not understand that even to talk to relatives, the permission of the patient is needed. When it comes to talking about end of life care, many people will say please don’t tell the patient as it will crush hope. For the most part, this is about the relative struggling to accept upsetting news rather than the patient’s ability to deal with it. These matters are even less well understood when it comes to Best Interest decision making, with the relative firmly believing that what they have to say will determine the decision.

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3. There is insufficient emphasis that when it comes to making a decision, this can only be done at the time a decision needs to be made. The current context of available information should impact on the decision being made and therefore this decision might be different to a prior similar documented decision: for example, if there exists a prior Advance Decision to Refuse Treatment and now a decision on treatment is required but the person lacks capacity to make it, the professional must undertake a fresh assessment of the terms of the Advance Decision in the current context to determine its applicability to the decision now being made (i.e. the ADRT should not simply be taken as applying automatically). This lack of clarity about having good information and contextualising it can cause confusion as to what the difference between an Advance Directive and an ADRT is, and what the legal basis is.

4. There are significant problems around the documentation of mental capacity testing. The MCA is quite specific about who can and cannot do this and how it is done, but in practice both the process of assessing mental capacity and documenting the outcome of assessment is extremely variable. This potentially creates two problems: first, that some professionals will oversimplify the process and record insufficient documentation, or second, that other professionals will be over-cautious and expect overwhelming amounts of paperwork and unnecessary numbers of visits to the person concerned in order to assess capacity. Clear paperwork can help to support good process, so it would be helpful to have examples of what good paperwork looks like and to be more specific about what is and is not acceptable in terms of assessing and documenting capacity.

5. There are similar problems with the process and documentation of advance care planning in people who lack capacity. We commonly find that the documentation of advance care plans in nursing homes for people who lack capacity is poor, with poor process that is so unreliable that it can become dangerous. A minimum standard for the process, with suggested or example documentation, would be extremely helpful in reducing variation and assisting care homes and safeguarding teams in particular.

Both Dr Abel and Dr Cartmell would be very interested in providing verbal evidence to the committee if that might be helpful to the review process.
Academy of Medical Royal Colleges – Written evidence

Introduction

The Academy has been asked to present evidence to the Lords Select Committee on the Mental Capacity Act 2005. As Professor Terence Stephenson, Chair of the Academy, is unavailable, Professor Sue Bailey, Vice-Chair of the Academy has agreed to represent the Academy. Professor Sue Bailey is also President of the Royal College of Psychiatrists, who are separately providing evidence in their own right.

This briefing has been built on information from individual members of the Academy and structured under four questions that Academy members were asked to comment on.

1. Do you think your members have sufficient knowledge of and confidence in using the Mental Capacity Act 2005?

It is the belief of the Academy that the level of knowledge of and confidence in using the Mental Capacity Act 2005 (MCA) is variable.

Some Academy members felt awareness was widespread and quoted training and awareness programmes provided by bodies such as Trust Legal Services, the ‘Safeguarding Vulnerable Adults’ training; specialty specific guidance such as ‘The management of visual problems in people with learning disabilities’ produced by the Royal College of Ophthalmologists; and the MCA is part of the curriculum at Membership and Fellowship examination stage of the College of Emergency Medicine exams.

Other Academy members had undertaken some audit and survey work and this indicated areas where knowledge could be stronger – for example, trainees in Emergency Medicine in some hospitals have highlighted this topic as an area in which they have little training and the Faculty of Intensive Care medicine audit indicated a low level of awareness of Independent Medical Capacity Advocates (though the Royal College of Physicians of London stated how impressed they were with IMCAs).

2. What aspects of the Mental Capacity Act 2005 you believe currently work well, and why?

A number of Colleges welcome the MCA in bringing clarity (at least to some areas), making people think about capacity, and providing a framework for decision-making.

The Royal College of Physicians of London sees the IMCA as very positive innovation, though the Faculty of Intensive Care has noted some concerns (see section 4 below).

An additional benefit has been the creation of a clear pathway for research recruitment for diseases that cause impairment of capacity in the Intensive Care Unit.

3. What aspects of the Mental Capacity Act 2005 you believe don’t currently work well, and why?

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Academy members feel there are areas of the MCA that could be clearer. For example:

- Lack of definition for deprivation of liberty in the Act or Code of Practice. Currently, the difference between “Restriction of Liberty” and “Deprivation of Liberty” is merely one of degree or intensity, not of nature or substance, and the final decision is made by the court based on the facts of each case.

- Presumption of capacity until proven otherwise. We often have to make judgements about whether a patient has capacity on very incomplete information. The best example of this is when a patient after taking an overdose absconds before they have been assessed by a clinician and staff have to decide whether to bring them back or not. Presumption of capacity until proven otherwise can make it difficult to persuade the police to bring them back. Perhaps a degree of “leeway”, where capacity is uncertain, would be helpful.

- Absence of an objective test for ability to “weigh up information” to arrive at a “choice” in the assessment of capacity. This element relies heavily on the practitioner to make a subjective judgement on the comprehension of data, which can be challenging in a patient whom you have just met.

- Difficulty with assessment of capacity in patients with learning disability. This is mainly due to problems with communication and difficulty knowing what their views and preferences are. There is also the problem of them consenting to a procedure without understanding the impact of the consequences of their decision. On the other hand, in a strange environment, especially after a long wait to be seen by a clinician, they may be distressed and display signs of challenging behaviour and be assessed as not having capacity to make a decision.

A more general uncertainty about how the nuts and bolts of the MCA should be applied to patient care is also felt to exist, with a sense that practice varies across and within Trusts.
4. Any other supporting comments you may have, for example changes or additions you would like to see?

Academy members have made the following additional comments:

- Mandatory training made to be more robust, particularly in relation to clear documentation.

- The IMCA service seems to be used very variably. In many instances, clinicians are not clear what the IMCA service can provide, and conversely, it is difficult to use a service that is only available Monday to Friday between 08.00 and 17.00 hours (at best), for a service that has to make critical decisions 24 hours a day, 7 days a week. There is substantial scepticism amongst many clinicians that a person who does not know the patient can make a useful contribution to decision making on a de novo basis. It may be that IMCAs can only provide a benefit in very restricted and specific settings, but exploration of the opportunities available and better refinement of their role would benefit from more formal evaluation.

- The provision of advance directives would greatly facilitate decision making in many patients, but this option is greatly underutilised at present. There would be substantial benefit in publicising this generally, and also ensuring that admitting clinicians consider this when undertaking high risk operations or treating high risk diseases in high risk individuals. Currently, there is a reluctance for admitting clinicians to bring this up for fear of seeming inappropriate, but we need to work hard to remove this apparent stigma, so that critical management choices can be made in the light of full knowledge about patients wishes.

10 October 2013
Academy of Medical Royal Colleges, British Medical Association, The College of Emergency Medicine, Royal College of General Practitioners, Royal College of Psychiatrists – Oral evidence (QQ 153 – 171)

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.

TUESDAY 15 OCTOBER 2013

Members present

Lord Hardie (Chairman)
Lord Alderdice
Baroness Andrews
Baroness Barker
Baroness Browning
Lord Faulks
Baroness Hollins
Baroness McIntosh of Hudnall
Lord Swinfen
Lord Turnberg

Examination of Witnesses

Professor Amanda Howe, Royal College of General Practitioners, Dr Julie Chalmers, Royal College of Psychiatrists, Dr Dorothy Apakama, College of Emergency Medicine, Professor Sue Bailey, Academy of Medical Royal Colleges, and Dr Tony Calland, British Medical Association

Q1  The Chairman: Good morning and welcome to the evidence session of the Committee. I am grateful to you all for attending. I should advise you that the evidence is transcribed, and also broadcast. So this session will be broadcast. Before starting, I should say that we only received evidence from the Royal College of General Practitioners last night—late last night—despite frequent attempts to get it in time for circulation to the Committee, but we will do our best to deal with the evidence that has been submitted.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Can I start by asking a general question to all of you? How do you reflect the Mental Capacity Act in standard setting, and how does that compare with the way other legislation, such as the Mental Health Act, is reflected in standards? Could I start with, perhaps, the Academy?

Professor Bailey: Thank you. Standard-setting is a central role for each of the Colleges. The Academy is involved in educational standards through the foundation programme curriculum and the common competencies framework. MCA does appear in the current foundation programme curriculum. It describes when and how to apply the relevant mental health and capacity legislation, but I have had a relook at it, and I do think the emphasis is on mental health. There could be a stronger emphasis on capacity and this could be strengthened.

The common competencies framework identifies the common competencies that should be acquired by doctors in core and specialty training in the United Kingdom. This has a learning objective on the legal framework for practice. What I would say overall is that the Academy has a limited involvement in clinical standards. The work we have been doing recently has been about patient-centredness. We are also developing some generic ethical decision-making guidelines. These are the two places where we want to place our emphasis and focus, working with patients and carers to move from paternalism to enablement in keeping with the MCA.

Dr Chalmers: Thank you. Good morning. The Royal College has an explicit statement about standards in its document Good Psychiatric Practice, which states that a psychiatrist must maintain knowledge of current mental health and other legislation as it applies to psychiatric practice, ensuring that it is applied appropriately in clinical practice.

Also, we set some relevant educational standards in our curriculum for core and specialty training. I have to say that, having looked at them, they are quite light and they could be built upon. Also, I think we could develop a more, if you like, master-class-type approach as trainees develop. Within their e-portfolio, in which they record reflections on their clinical contacts, experiences and workplace-based assessments, there is a section for mental health legislation work. That section could be used more fruitfully to reflect upon their experience of detaining people under the Mental Health Act, as well as their use of the Mental Capacity Act. That is certainly something I would like to work with Health Education England on developing further.

Also, for Section 12 and AC approval, these are statutory roles within the Mental Health Act. As part of the mandatory training, there are standards set by the national reference group to include the Mental Capacity Act and deprivation of liberty safeguards training, so that is embedded in more senior training. More recently, the College has started to work with CQC to look at what does “good” mean in clinical practice and setting standards, particularly for the Mental Capacity Act. This is a particularly difficult challenge because, unlike the Mental Health Act, where there are clear things that you can count and then follow up—for example the number of detentions, and then you can follow up the process—the Mental Capacity Act is more about a philosophy of care and a spirit of enablement. Capturing that is rather more difficult, and we need to be looking to proxy measures. What I am highlighting is: it is a challenge to get that right and to see if it makes a difference to patient care.
Finally, the College's Centre for Quality Improvement sets certain standards and benchmarks against national standards, and has an accreditation for in-patient settings. It covers general adult psychiatric wards and also learning disability wards and wards for older people. The learning disability standards are very explicit, stating that the Mental Capacity Act must be followed. It talks about best interests, and there are several statements alongside that regarding standards of implementation.

Professor Howe: Good morning, thank you—apologies for the late arrival of our written evidence. Should you wish to ask us questions or explore anything further after the hearing because of that, we would be happy to receive them. It was due to capacity, staff changes—the usual difficulties in a charity—but, apologies.

In terms of setting standards for our college, I would say three things. The first is the question of testing capacity in the Mental Capacity Act appears in our curriculum, and it is applied in our different modalities and assessments according to the blueprint of the assessment that we provide for the exit exam. Not all GPs are our members, as you will probably know, but GPs have access to the curriculum that we use to train our graduating doctors for general practice. Through appraisal and revalidation, people can map their own learning needs onto that curriculum. So I think the Mental Capacity Act is very much visible to GPs in general.

In addition, we have undertaken three pieces of work in the past years around this. One was to provide direct guidance through a toolkit around the Mental Capacity Act, because where we cannot always set standards for continuing practice, we can give detailed guidance and encourage people to use that for their educational process. We have a substantive piece of work through collaboration with the Princess Royal Trust on carers—support of carers—and commissioning guidance for support of carers under that.

Then, within our training and curriculum, we have recently been reviewing the curriculum to support our application for extension and enhancement of GP training from only three years to four years. Within that revised curriculum, we are, in draft, increasing the embedding of competencies around capacity in the Mental Capacity Act.

The other thing I would like to point out is that, as my colleague has said, in general practice we largely assume capacity. That is the nature of our population. We are working in the community, where most people are living with some independence. It is quite a different context from people working with in-patients and emergency care. We spend a lot of time in training emphasising the generalist competencies that underpin capacity and testing of capacity. Those are: listening, understanding and shared decision-making. These are all deeply embedded in the training that we now give our young doctors and, indeed, with my medical school hat on, I would say that most medical schools at undergraduate level are also really emphasising these generalist competencies, which one would then tailor to the patient in front of one according to their ongoing needs and the needs of that encounter. That is where most GPs find that they can then work with the particular demands of the Mental Capacity Act when and if needed.

Dr Apakama: Thank you. The Mental Capacity Act is very high on the college agenda. It is part of the curriculum and formally tested at Membership and Fellowship.
Dr Calland: Thank you. Good morning. The BMA, as such, is not a body that sets standards in itself, but, as service to our members, we have a responsibility to give them information and keep them up to date with changes in the law and medical practice. We have done quite a lot of work on that score. We have got a Mental Capacity Act toolkit, which is available to members, and I have some copies here that I will leave for you. We have worked with the Law Society on the assessment of mental capacity, and we have two major publications, *Medical Ethics Today* and *Everyday Ethics and Law*, which is a smaller version of *Medical Ethics Today*—a handier version—which contain considerable amounts of information about the Mental Capacity Act: when it needs to be applied, and how to judge capacity. From our point of view, the standards are already set, and it is our role to respond, and we feel that we do as much as we possibly can within our resources to supply that information to members.

Q2 Baroness McIntosh of Hudnall: Listening to all of you, it is clear that you have, in various ways, tried to take the requirements of the Act very seriously. The question I am about to ask is liable to sound a bit rude, but it is not intended that way. There is no question that in the great volume of evidence we have so far received—written and oral—there is a strong sense that non-compliance is quite widespread, particularly in medical settings. This appears to be—I am choosing my words carefully; I hope you are noticing this—more evident in relation to general practice and emergency medicine than other branches of medicine at the moment.

I know, because I have briefly read the evidence that the Royal College of General Practitioners has submitted, that you, Professor Howe, would want to challenge that evidence. You have certainly suggested that it is open to challenge. But I would like—we would all like—to hear from you and Dr Apakama in particular, but also from your colleagues, about why you think there is this evidence coming to us that suggests non-compliance. What research, if you think the research is not reliable, have you either undertaken or could undertake that might uncover what is actually going on? Clearly, the training part of it is being delivered; it looks like it is compliant.

Dr Apakama: We, as a college, have not undertaken any research, and therefore we have not got any reliable data on the level of compliance. However, anecdotally, we have evidence that the level of compliance in emergency departments is variable, but generally, it is very good in most hospitals. The College would be interested to see the evidence that ranks the ED as one of the worst performing areas, so they know what specific areas of concern to address. However, the evidence we have gathered suggests that the level of compliance is variable, but generally very good.

Professor Howe: Of course I would acknowledge, as would my colleagues, that previous witnesses have given evidence that there are some problems. I think we always know that, in a large population with a diverse workforce with many different needs, from time to time there may be things that we wish could have been done.
better. It is part of our normal professional mechanism to try to encourage people to learn constantly and to update themselves and their teams and colleagues when they think things need to have been done better. If a carer or an independent advocate comes and says, “I would like to challenge you on that one,” I think we would be likely to listen.

Having said that, we have not had many examples brought to our attention of the sort that you have had from witnesses, and I did wonder—I was not quite clear—reading some of the previous transcripts, how many of those were third-party stories and how many were directly witnessed consultations. Because, again, in an expert consultation where one is constantly making a choice with the person in front of you—or the people in front of you—about what is needed and how best to spend that time, I know, from teaching students, that sometimes people watching me will not know all the processes that I am going through in my mind in order to come to a conclusion. It is part of the job of a teacher to explain that. So maybe some of it, I would like to think, is not that we were not doing the job but that we were not explaining how we were judging capacity. However, I do not know about your examples.

Q3 Baroness McIntosh of Hudnall: I think, to be fair, it is not our job to examine whether or not you are doing your job right. Our job is to look at the legislation, and therefore one of the things that necessarily occur to us, thinking about the evidence that has come in, is that there might be something wrong with the legislation that makes it difficult for people to comply. Now, one of the things that is peculiar about the evidence is that almost everybody says this is wonderful legislation. Then, quite a few people say, “But actually it is really difficult” or “frequently not complied with.” So, if you have something to say to us about the difficulty of complying with the legislation, that would be very relevant if there are difficulties.

Professor Howe: I promise I will come back to that—in fact, I might address it now. I know, from members, that of course time is a problem in many settings in the health service, particularly at the moment: our workload, the number of consultations we do, the complexity of our task and the opportunities that we have to help patients and their families have hugely increased in the community in the last 10 to 20 years. Our workforce, frankly, has not expanded to fill that place.

Having said that, one can still do a good job even if time is limited, and I do not think that stops us having that professional responsibility. In terms of research, the College does not have its own research unit; we respect and leave that for our academic colleagues from primary care backgrounds. However, as it happens, I have a doctoral student who has just submitted his thesis and he has given me permission to give you a little bit of information from his study. It showed that the GPs and practice managers whom he interviewed as part of his study were very familiar with the Mental Capacity Act and, on the whole, felt comfortable with it as good, clear guidance where bodies like mine had then helped to translate it into very practical application: “How do you test consent?”; “It’s in the toolkit.” They were less comfortable—I do not know whether you will want to introduce this—when one comes to the question of advanced care planning and the rules and regulations around that. That seemed to be a professional area where people were still needing support and help about the status of the GP, the obligations of the GP in that, and the recording of information. So, one of the difficulties, apart from time, is how you
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keep effective recording that travels from person to person. We have the same problem in general practice as I expect my colleagues in emergency care do when patients are moving across an interface about whether some record of best interests or capacity from a previous round still applies. It is our job, if we have a new situation, to test that again anyway. For example, if I discover a new clinical problem with a patient who has some cognitive impairment who has come with a carer, or perhaps not come with their main carer, it is my job, of course, to re-examine any new decision in the light of that person’s capacity to understand the choices and implications of those choices.

However, it is an even bigger problem if there is data that they have previously recorded somewhere else that then has not travelled in a clear way through the records. That is another need that we have identified: not necessarily the competence of the professional, but the surrounding formal paperwork or record that is needed to be able to understand the legislative side of the framework for professionals. We can do that work with a colleague in front of us, and their families. However, if there is documentation from elsewhere, it is important that it travels in a recognisable and repeatable form. Variations in forms, frankly, do not help us, because they do not have that recognition factor when you are busy.

**Q4 Baroness Andrews:** With respect to the evidence from the Academy of Medical Royal Colleges, you do address this question of aspects of the Act that you do not believe are currently working well. Yet, when you go through your list, some of these, particularly the last bullet point about the difficulty with assessment of capacity, seem to me to be something that would be very difficult to improve in legislation, as indeed would an objective test for weighing up information. These seem to me to be more to do with process and judgement than improvement of legislation. I wonder if you would like to pursue that and clarify how you think the Act might help with the sort of judgment your members have to make on a daily basis.

**Professor Bailey:** I agree with you. It would be difficult to improve that through the legislation. There are issues around deprivation of liberties which my colleague would speak to. What is fundamental to this is what appears to be evidence of variability. Going back to the colleague from general practice and the level and state of health informatics, you could capture change, so that you would know what the state of play would be. You would be able to see change because there was better health informatics. This would help.

I think, fundamentally, it is something that needs to be bedded in more from the first day in medical school, so that it is a way that medical students—young doctors—are constantly thinking from the start of their career all the way through. This goes to the heart of what, to me, would be a practical output from the training that you receive in medical school, about ethics and ethical governance. In a way, the Mental Capacity Act is a very good template. That leads on to where that would lie with workforce training across the workforce. But particularly talking about doctors. I was able to speak to Health Education England yesterday, where I co-chair the medical professional board. They have set up a mental health advisory group—just set up—which will be all the professions across the whole of medicine. This is where more work could be done about what is needed: so bedding it in from day one in medical school to the day when I stop clinical practice. This is a
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root-and-branch thing that cannot be stop-starting in fits; it needs to be dynamic and it needs to keep going. Of course, those are things that are easy to say but difficult to do.

The Chairman: Can I ask how you respond to decisions or criticisms of the health service ombudsman? There was a recent case concerning a GP who did not prescribe suitable medication, on the basis of cost alone, to a patient who had learning difficulties and epilepsy. This was a failure to consider the GP’s obligations under disability discrimination law and a failure to apply the best interest principle. How would you respond to a finding of that nature, and how are these reports incorporated into your standard setting by disseminating the key findings and providing advice?

Professor Howe: In terms of the Royal College’s response, we tend to use examples of where difficulties in performance have arisen in three ways. One is that we may embed them into further training guidance. So, just as a medical defence union might do, we use a case example where things have gone awry to show how one could do better in another setting. We may use them to lobby on the difficulty that doctors may be put in, because I do not know the detail of that case, but we are, in general practice, constantly being asked to drive down cost and to switch scripts in order to save cost. On the whole, the NHS thinks that is good practice, providing the product is equivalent for the patient’s needs.

I am implying, but I do not know, that in that particular unfortunate incident, perhaps the drug was no longer appropriate in a way that the GP perhaps just did not understand. We would also be going back to commissioners and people with costs saying, “Look, if you want us to keep within cost budgets then you must not tell us off for going for the cheapest generic alternative, because if there is a need, we will have to stick with that patient’s needs.”

The third thing comes back to informatics, because some of the evidence about prescribing errors from Tony Avery’s group showed that, in the process of switching scripts and drop-down menus, sometimes errors happen that you do not pick up, the pharmacist does not pick up, and the rest is dreadful.

I think that we do training from learning from cases. I certainly have learned a lot from preparing for today, and I fully intend to take my learning from this back into my college and use it for training guidance, because we are always updating the curriculum—the training, the guidance. But also I think we do have to answer some difficult questions on behalf of GPs about why that GP felt obliged to change a drug for the sake of cost and how the fact that it actually was not in the patient’s best interest arose. In other situations, we are told that it is in the best practice of our population to save money where we can.

Q5 Baroness Hollins: Much of what I want to ask you about in terms of training has already been answered, but regarding the point that Professor Howe has just made, with respect, I want to push you a little bit further on that. I suppose it is about your understanding of the evidence that we have seen and that is in the public domain—some of it—for example, the findings of the recent confidential inquiry into premature mortality of people with learning disabilities, where decisions are being made and the Mental Capacity Act, it seems, is certainly not being followed. I am thinking about the evidence that showed that women with learning disabilities were dying 20 years earlier
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than other members of the population; they were suffering from the same condition as other people, and they were getting different investigations and different treatment.

That is the issue: the excuse might have been cost, but actually if other patients with the same condition are getting the drug, then there are issues about both the Equality Act and about the Mental Capacity Act. For me, the question is this: if you are convinced by the evidence that there is variability of practice, what actual implications does that have for the changes you are going to make to your training? That, to me, is really important. How do you take it back? Not everybody is going to have the opportunity you have to prepare for today and to really reflect on it. How do you take that learning back to all GPs? It is a question, in a way, for all of you. When some bad practice is presented or when things have not been properly bedded in, as Professor Bailey put it, how does the training change to accommodate that?

Professor Howe: There are two different parts to that answer, if I may. First of all, we had already committed a lead for our college—Dr Matt Hoghton—to doing concerted work on the needs of patients with learning disabilities and their rightful expectations of us as GPs. Matt was on, I think, the confidential inquiry. He is, with others, the author of the toolkit that I referred to earlier. Because of our recognising this problem and appointing him to play a leadership role in our college for this particular group of people, he, with the BMA, has prepared other material, and we roll that out: we make it available; we put it on the website; we put it in the curriculum learning resources. We refer to it when we are thinking about setting the exam and we encourage trainers to use it. That is why I agree with you and we are already on to it.

In terms of ongoing variation in performance, I think every time a group like yours comes back with recommendations, as well as us trying to take an initiative and be proactive, we try to listen. When people give us findings that say, “Not good enough,” we will, hopefully with others, if they wish us to, try to update guidance, update the curriculum, and run out new learning packs.

I will say, of course, that we are a generalist college, and for every particular task there will be other tasks that also matter to groups of patients that we also have to give guidance on. We cannot always be working on updating something every six months, because we might have 150 topics to look at. However, we do take on recommendations of a group like this, and if somebody comes to us, as did the Princess Royal Trust, to say, “We would like to work with you. Here is a project and here is some funding. We would like to do this with you,” we may well take that on. We have another track record in working with the Department for Work and Pensions: running out training classes, preparing DVDs and putting e-learning online. All those are open to us if the topic and capacity permits.

I will say, however, that in terms of individual practice variation in performance, or commissioning-group-level variation in performance, the College does not have a regulatory or an inspection role. That is left to others. So although we engage with commissioning—and we have a commissioning lead for exactly that purpose—and we engage with CQC, we do have to leave specific examples, where people consider there has been underperformance, to us learning from it but not doing the inspectoring side. Does that help you?
Q6 Lord Alderdice: I would like to press a little further along this training route that Lady Hollins has picked up on. As Lady McIntosh says, our main interest as a Committee is in the legislative side of things. However, it may not be that the problems are entirely susceptible to legislative changes. Dr Chalmers was quite rightly saying that there is almost something about the culture of one’s approach that is important. Professor Howe, you were saying, “Well, we treat everybody as having capacity until proved otherwise,” as it were. However, there is a bit of a difficulty about this in terms of how one approaches patients with various kinds of disturbance.

For example, if you are working, as you know, with a patient with psychosis, it is very easy to be seduced then into paying attention to the psychotic elements. One of the things that we often say to trainees, as a sort of shorthand for this, is that it is important to try to engage with the non-psychotic part of the personality in order to build up a human relationship—not failing to pay attention to the psychosis, but you have then got a relationship and something to work with. However, that requires training, not didactic training but often supervision and working clinically to bring people along. Of course, in general practice, it is more difficult because you are shifting so quickly from this patient to this patient to this patient.

There are also some equivalent issues about dealing with the healthy part of the personality in someone where there is mental incapacity, whether it is in the patient with dementia or some of the patients we are dealing with here. I wonder how far that component of the clinical engagement gets paid attention to in training, where you have to accept that simply dealing with every patient, as it were, as though they are fully competent when they come along until proved otherwise, can actually lead you off in the wrong direction. I guess it is probing this question of training: not so much training in the Act, but training in the way of engaging with people who are susceptible to the Act.

Professor Howe: In general practice, our training is, in our view, now too pressurised to do the full leadership and competent job that you want from today’s GPs. Nevertheless, we do have the advantage of having one-to-one or one-to-two supervision of clinical training in general practice for at least a year out of the training scheme. So, as a trainer—when I was a trainer—and for my colleagues who are still trainers, it was certainly part of our agenda to help our trainees to become competent and confident with patients with all sorts of problems on an ongoing basis. Because we are seeing people outside the acute emergency situation—check-ups, reviews, follow-ups, learning disabilities, patients with severe mental health problems, people with neurological impairments—it is particularly part of the trainer’s job to help the trainee to look after those people whatever their need is coming in.

As you say, the curriculum is one thing—knowing it is in the curriculum is one thing—but going to somebody, working with them, working with their family and coming out having, hopefully, done a job and worked with them to make the choices that they can make, and perhaps also to be having discussions about best interests and what that means in practice, is something that we would put to the clinical supervisor. I am sure that our trainers would cover that in the core curriculum over the time that they have the candidates. We also have peer learning groups and vocational training, where people bring those cases back and can work with them with educational supervisors as well.

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Dr Chalmers: Two points: first, I am rather old-fashioned and grew up in the apprenticeship way of learning. I think that consultants can lead and help their trainees develop. But I also think that, as psychiatrists, we have the benefit of working within multidisciplinary teams, and nurses often forge relationships throughout the journey of somebody with psychosis—from being unwell, when we, as doctors might be very closely involved, to being well again. Working in a team, you can speak to that well person with the assistance of the nurse. We can reflect back, that we know when they were well, this is what they told us that they would want. That is the person that we want to have the discussion with. This is where—as someone who has been in my post now for a very long time—continuity of care is essential. Some of these very old-fashioned values are desperately important here.

With regard to training, I come back to keeping it very simple—very simple messages to people. Again, it is about creating a culture. You may be familiar with the FRED&A principles. It is about the basic human rights of fairness, respect, equality, dignity and autonomy. If you just hold on to that—“Am I acting as FRED&A would?”—you can go a very long way. This is a message that is easy to get across. You do not need to do two hours of training on the Mental Capacity Act and Codes of practice. If you hold on to that simple message, that would enhance training. I do come back to how it is about developing a culture and endorse Professor Bailey’s view: start early and stress the importance of these values across all disciplines.

Professor Bailey: Thank you. This could be added to each and every clinical encounter. So you have happened to see a person with capacity who is 26 who has a particular illness. Following that encounter, you could say, “Right, how would you think about that? What principles would you apply if it were somebody with a learning disability, sensory impairment, a six-year-old, a 16-year-old, a 96-year-old, with or without forgetfulness?” It is about reminding medical students and doctors at every clinical encounter that you can learn from each encounter you have, think more widely about people you see as challenges and dilemmas, and look for shared solutions.

Q7 Baroness Browning: Could I just ask, particularly Professor Howe, about the Royal College evidence, where it was suggested that GPs should include a capacity check in the annual health check-up? I can see that, perhaps for people with dementia, that would be a very useful thing to do and there would then be an easy referral route, but for learning disability and particularly people on the autism spectrum, it suggests using the step-by-step guide that GPs use. I wonder what sort of training could be given to make an appropriate assessment of capacity with both learning disability and autism in that very short period during which the check takes place.

Professor Howe: It is a good question; it is one I have been thinking about quite a lot. As I said earlier—I think it probably is worth exploring a little bit more—our good practice in consultation will start from looking at the background of the patient coming in: whether or not we already know them well personally, but also seeing what has been going on, looking at any recent encounters, looking at statements about carers. So, records—they come in. How do they come in? Do they come in alone? Do they raise the issues for their annual health check that they want to raise or are they mute? Are they distracted? Have they come in with somebody else? All these things are evidence as a clinician that you gather straight away.

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The annual health check is based on research evidence. So, in the professional sense of the word, we are assuming that it is in the patient’s best interest to carry out those actions that are appropriate for their clinical care unless they dissent. So, if they are on anti-epileptic medication that needs an annual blood test and that is what research tells us, that is what we are going to aim to do with them unless they dissent. So I think what we meant there is that we would use the opportunity of a non-acute situation to check that the patient is as enabled as they can be to be engaged with their health care and also then to record any issues that might arise from that: any observations about difficulties in communicating, making choices, retaining information. The step-by-step guide simply gives GPs a framework. A bit like FREDA, we are using CURB to work their way through the things they need to consider.

After the health check is over, there might be a question about how much that was being used to make a proactive plan. The college has been debating, “Well, if we are going to do care management and raise our game, how do we do that?” We have some work called the Year of Care that you might be interested in, where we have already been trying to develop the right model to take that work forward with people and their carers. What does that mean in terms of time? What does it mean in terms of organising or reorganising services? These are big issues regarding using general practice and its teams to the best of ability. However, in terms of the encounter itself for people with autism, I suppose that as a GP, at the end of the day, when that person is in the room with me, I just try to use my best skills to make them comfortable, to allow them to communicate with me, to check anything about capacity to consent that I need to and then, if they allow me to, to do the full job.

Beyond that, if things go awry—say, we get to a certain point but then they do not want the blood test—I am back into, “Well, this is not urgent. It may be temporary. We may be able to calm things down and come back to that.” I may stress that they come back with their carer or colleague next time to try to offer them, again, the thing that in every other way we think is in the evidence as important to them.

**Q8 Lord Turnberg:** Having heard all about your very impressive training programmes, how comfortable, at the end of the day, do you feel your trained individuals are in assessing a patient’s capacity compared, for example, with assessing a patient’s physical requirements? That is for all of you.

**Professor Howe:** Well, I have talked quite a lot, so I will sit back and come in later perhaps.

**Lord Turnberg:** How comfortable are they with assessing capacity?

**Dr Apakama:** The staff in the emergency department deal with quite a lot of cases that require the assessment of capacity. It is done on a daily basis. I cannot remember the last time I did a shift and I did not have to do that many times. From my experience, the ED staff are very good at it. For example, if there has been a need to detain a patient under the Mental Capacity Act, and I am probably busy doing something else and somebody comes to me and requests that I review the patient, when I do, I usually find that their level of capacity has actually changed. It is one of the things that we document on the forms. We have to review the capacity regularly to ensure that restraint is not used beyond when it is indicated. I am very confident with the doctors in order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
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and nurses in the emergency department, because they get quite regular training on MCA. I cannot speak for other specialities.

**Dr Calland:** I was a general practitioner in my career. I am now retired. One of the difficulties that a general practitioner has is that, as has already been mentioned, there is a complete change of direction with each patient that comes in: you will be dealing with one thing one minute and something completely different the next.

Issues of capacity are, in some ways, if you are in a hospital setting with somebody who is unconscious or seriously under the influence of drugs or alcohol, a big thing. It is obvious. With general practice, you may well be dealing with several issues with the same patient, of which capacity may become one of them, but it is not necessarily the primary thing that walks through the door with you. Assessing capacity is usually not something that you do four times in a surgery. It is something that happens relatively infrequently amidst all sorts of other things.

Therefore, there is a difficulty for any individual doctor, however well informed they are, in suddenly switching from their heart failure, or their diabetes or whatever, to their capacity: “Do I have to assess this? How seriously do I think they are incapacitated?” If somebody comes in with their relatives and wants to change their will and it is a question of capacity, that is quite easy to deal with, and I think most doctors would probably manage that with a reasonable degree of competence. I think the difficulty arises when it is rolled in with many other issues in the consultation, and capacity may not be the primary issue when the patient walks in. There is some real difficulty to guarantee that the legislation is going to be complied with completely in those difficult circumstances.

**Dr Apakama:** Throughout the patient journey, from admission to discharge, we are at every stage expected to obtain informed consent. Capacity is one of the elements of informed consent. Starting from taking the blood pressure in the triage room, one is expected to obtain consent, whether it is implied, verbal or written. So, throughout the process of the flow of the patient from admission to discharge, we do assess capacity because it is part of informed consent.

**Dr Chalmers:** I think psychiatrists are generally very familiar with the legal test of capacity. I actually think the assessment of capacity can be quite difficult in clinical practice. The legal test requires a binary assessment of whether capacity is present or not, on the balance of probabilities, and, therefore, this can be a very fine balance. On the same set of facts, two practitioners could come to completely different conclusions.

Psychiatrists have to work with difficult areas of capacity assessment. For me, there has been an overreliance on the cognitive component of the capacity test, whereas there is a very difficult third part of the test: the weighing in the balance. What does this actually mean? Sometimes people think this means: “Is this a logical progression of thought?” However, in the situation where somebody just does not believe that they have the illness, they do not appreciate that what you are saying is relevant to them. I think that is relatively familiar to psychiatrists in the presence of a psychotic disorder, if it is relevant to the decision in question, of course.

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However, I think that the effect of emotion is very underplayed. I am very concerned in cases of people who have borderline personality disorder, who have problems with emotional regulation, and who can be seen in A&E in a borderline storm, if you like, of emotion. They can understand the treatment proposed—the fact that the paracetamol overdose will kill them—yet sometimes their emotion can cause them to have problems weighing things in the balance. I think there is a difficulty for some of our non-psychiatric colleagues in fully appreciating that.

Having said that, I have also seen excellent practice with regards to capacity assessment and the presence of advanced decisions in A&E. The legal test is clear, but in clinical practice it is far more difficult. If I could return to the people who have autistic spectrum disorder, I think we are recognising them more and more in general adult practice. I think they do need a very particular approach. Just to return to your point about training, people with ASD are the best trainers. They can tell us the experience of how they perceive the world, which can be very different from how we think. Our kindly approach sometimes with complicated explanations does not work, and we need to learn to be rather clearer and less metaphorical. So, having experts by experience, particularly in this case, is very valuable.

Professor Howe: Returning to your question about how confident our trainees feel at exit, if you went to a cohort of our trainees just having finished MRCGP, they would say they are—I think they are—competent but they do not feel confident. That is because they still would benefit from some time under supervision, particularly working with these more complex clinical cases, as well as gaining these service development needs. This is part of our rationale for really pleading to have enhanced training, because it would give us more time to work with these issues, as well as the service development and the practice management level. I also think it is a question of how one asks the question. So if you say to a young doctor, “Do you feel competent and confident to apply the Mental Capacity Act?” they will probably say, “No,” because they are humble and they know they are early in their careers. In fact, again, because we have done the generalist training about how to communicate and how to adjust yourself to the needs of different patients and to understand their needs, I think they are probably more competent than they often think they are. However, they deserve a little more support with that.

Q9 Baroness Hollins: This is a question for Dr Chalmers about revalidation. In your submission, you outlined a programme of auditing individual psychiatrists and implied that something was stopping you from taking it forward. Can you explain?

Dr Chalmers: Yes. As we put forward in our evidence, there is the College Centre for Quality Improvement, which is a commissioned service within the College. This sounds like a bid for finance; in many respects it is, so I will carry on with this. The College Centre for Quality Improvement sets standards for organisations in the delivery of mental health services, engages with front-line staff and supports them to measure their own activity and their own service against these standards. It also works with teams, which is essential in thinking about the delivery of the Mental Capacity Act because, obviously, individual practice is important, but often it is a team culture that is important as well.
The particular proposal that we put forward in the evidence was regarding individual practitioners. The proposal that I summarised in the evidence was written by Professor Mike Crawford, who heads up the centre. He is suggesting that, with funding, the Centre could identify clinically relevant standards regarding the MCA. They could benchmark individuals against national standards, much in the way that the College has 360-degree assessment. A large domain, as you probably know, is about interactions with patients—seeking patient feedback—and you benchmark your performance against other people. It seems that you could do that for the Mental Capacity Act and also for Mental Health Act activity. It is a proposal. I think it would be a very valuable proposal, and we are looking for people to sponsor it, please.

Baroness Hollins: Are any of the other witnesses aware of similar proposals for auditing individual doctors?

Professor Bailey: I did ask across the other colleges and I do not think there are. There is an opportunity to learn from what is happening.

Q10 Lord Turnberg: One of the frustrations for the Royal College, as I know to my cost, is the mismatch between all the grand plans that come down from the colleges and are put out and practice on the ground. When you get out and about, it becomes rather more difficult. This question concerns paternalism. It is quite hard not to appear paternalistic when a worried patient comes along anxious about their symptoms, seeking advice, and the doctor gives advice. That seems almost inevitably to have a paternalistic element to it. It is particularly important to avoid that—to guard against that—when you have a worried spouse or a child coming along with a husband or a wife who seems to be deteriorating mentally and there is a concern about their capacity. How, on the ground, does a GP—or a busy, rushed, sometimes chaotic A&E department—find the time in a 10 or 15-minute interview to go about this whole business of assessing capacity and not finish up rushing and overriding the needs of the patient? It is a practical issue.

Professor Howe: In general practice, the first point is with the good consultation style that I tried to outline earlier. One is always going to start with the listening and clarification phase. We do have the advantage in general practice of being able to bring people back. As a GP myself, my norm—and I had a consultation just like that last night—is to get so far and then to agree with the couple concerned that they will mull over the stage we have got to so far and we will carry on that discussion. That is not the situation, of course, when somebody is acutely unwell. Then I suppose that, with a more rapid assessment, one might have to agree that the best interest is that somebody will be admitted. But in general, in general practice, the way I deal with it is by carrying on the conversation until it reaches a conclusion that the patient and their family seem to feel will stand for the moment in time.

Lord Turnberg: And the queue of patients in the waiting room.

Professor Howe: Yes, but, that is why I say, “We have overrun a bit”, usually patients are more aware of time than I am; after all, I can stay. I will say, “Let us make another appointment. Let us carry this on. You have a think about what we have discussed. Have a look at this resource. Here is an appointment for a fortnight’s time.” That sometimes has the advantage both of allowing me to test temporary impairments of
Dr Apakama: In the emergency department, as we all know, we deal with different groups of patients in very difficult circumstances. What constitutes the patient’s best interest is reached by considering the circumstances of each individual case and reviewing all the relevant factors. It is not always possible to do that in an emergency department, so what we do is use our judgment, and deliver the care based on objective clinical best interests until we can obtain further information from the relatives or carers.

Dr Apakama: We do have support staff. Initially, we have the healthcare assistants and the nurses. We can call Social Services staff if we need help. Usually, if we have to, I spare the time. We have a triage system, and those who have minor injuries might have to wait longer while we deal with these difficult cases.

Dr Calland: I was a medical student in the latter part of the 1960s and, if one looked at paternalism then and paternalism now, there has been a sea change beyond all recognition, really. One of the issues is, when dealing with patients, there is a balance between paternalism and medical knowledge and expertise. Very often, you can involve the patients in discussions, but because you are the person with the knowledge, expertise and experience, you are inevitably in a position of greater power and it is difficult to get away from that. You can involve the patient as much as you like; very often, the patient will say, “You make the decision, doctor.” Whether that is right or wrong, it is frequently what will happen. However hard one tries not to be paternalistic, some people may see that as paternalism.

Dr Apakama: I do not think so because, as I mentioned earlier, we do test capacity right from the outset. From the moment the patient arrives, starting from the assessment through to treatment, we apply the Mental Capacity Act. If, for instance, somebody comes in with a head injury and their blood pressure is taken, and they give implied consent, we do check capacity before we get that implied consent. Later on, if we suggest that they should stay in for a CT scan of their head and they refuse, we have to check their capacity again, because capacity is time-specific and decision-specific.

Dr Apakama: I do not think so because, as I mentioned earlier, we do test capacity right from the outset. From the moment the patient arrives, starting from the assessment through to treatment, we apply the Mental Capacity Act. If, for instance, somebody comes in with a head injury and their blood pressure is taken, and they give implied consent, we do check capacity before we get that implied consent. Later on, if we suggest that they should stay in for a CT scan of their head and they refuse, we have to check their capacity again, because capacity is time-specific and decision-specific.

Baroness McIntosh of Hudnall: That is very clear.
Dr Apakama: It might appear to someone that we are checking their capacity because they have refused treatment, but that is not the case.

Baroness McIntosh of Hudnall: Do you sometimes check capacity because somebody has refused treatment?

Dr Apakama: For every procedure and for every intervention. If, for instance, they refuse to have their blood pressure taken, that is a different situation and a different decision. If we now decide that we would like to admit them and they refuse to stay in hospital, we check their capacity again to make that decision, because that is a higher level of decision than just taking your blood pressure. It might appear to some that we are doing that because they have refused to stay in hospital, but that is not the case.

Q12 Baroness Barker: I want to echo Baroness McIntosh’s earlier comments about the purpose of this being to see whether the law is fit for the purpose for which it was intended. In Section 4 of the law, there is the statutory test of best interests. It sets out the criteria and it sets out the people who have to be consulted. Many—I emphasise many—of the submissions that we have had have said that medical professionals do not distinguish between the test of best interests and what they believe to be their own professional clinical judgment about what is best for the patient. Do you understand why that criticism is happening? Do you think it is fair or do you think it is a problem?

Dr Apakama: As I explained earlier, we do not always have enough information. You need to have enough information to make a decision about best interests. We hardly know what the patient’s previous wishes, beliefs or values were in the circumstances, so we will initially, in emergency situations, deal with the patient based on objective clinical best interests until we have obtained further information. By the time that happens, most likely they will have been referred to another specialty.

Baroness Barker: I think we can appreciate that, in emergency situations, it is perhaps different, so it would be interesting to know from the rest of the panel what they think.

Professor Howe: We have to respect the weight of evidence that you are telling us you have heard. As a researcher, of course, I always think about whether those are fully representative cases, whether they are typical, or whether they are coming forward because they are worrying but unusual. There is something about the epidemiology of the evidence. I certainly have not been able to say that I have found a study that shows where we are at in general practice in this regard. As I said, my young colleague’s study suggested that GPs and practice managers he saw were comfortable with the principles of the Act, found it helpful and thought they were applying them in the modern consultation which is a fairly flat hierarchy, I would say, in most settings.

Nevertheless, if we do have a bias, it will be to think that we know that, “This blood test is in the patient’s best interests, because the research says so and we had better get on with it.” If the Select Committee finds that we need to come back to our members and say, “Be more aware, colleagues, that you really do need to avoid the Bolam paternalistic position, because it is still drifting into some cases”, we will do that. That does not make the legislation unfit; it is probably more a question of us re-emphasising what it means for modern clinical practice in the ways that we are already trying to do. In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Baroness Barker: I think—to quote you—that we are striving to find the recognition factor for when you are busy. That is what you said to us earlier in the session.

Professor Howe: Yes. I recognise that of myself, although I still think that the context of general practice is that we assume capacity and we train people to work with that person in the room to empower that person, and so, if they dissent, they dissent; if they have capacity, that is their choice. I just have to be sure that they have understood all the options and, as I said to the colleague earlier, we often use time to check that out together. If the decision stands with them and the family, it stands.

Dr Chalmers: Perhaps I could comment from the psychiatric perspective. I would hope that as psychiatrists we would aspire to work alongside our patients, and we are more familiar with working in a way which mirrors the Section 4 of the MCA process so that the care-planning approach would involve hearing the patient’s views, often with the relatives and the professional carers contributing as well. I think we are already, in some sense, a step ahead, because that is what we are doing on a day-to-day basis, and I recognise our context is very different to that of other colleagues. The Act has empowered psychiatrists to take difficult decisions. The best interests process of having a formal best interests meeting has been incredibly helpful to me as a practitioner to make some very finely balanced, difficult decisions that are not about whether somebody should have an antipsychotic or not, but, for example, a very difficult situation about whether a very severely psychotic patient who was in in-patient care should have a termination of pregnancy—a really very difficult decision. This was before the MCA, but we used a best interest process. A number of my colleagues have been very supportive when we have suggested that we do this formally.

I would like to bring to your attention, because I think it has been a little lost, an excellent document that was commissioned by the Department of Health at the time of the implementation of the Act, by Theresa Joyce from the British Psychological Society, on how to undertake best interests meetings. When I bring this to the attention of my colleagues, they often come back and say, “Thank you very much. That was helpful”, because you are pulling in the whole team as well as the patient and family to make very hard decisions. As I say, I think it has empowered us.

Baroness Barker: Dr Calland, the BMA has proposed that best interests can include the interests of a third party. Could you expand on that?

Dr Calland: Yes. The way that we look at best interests is that it is not purely the clinical interests. One has to take into account the person’s relationships, the world in which they live, and their emotions. As a general practitioner, I was in a relatively small rural practice. I knew most of my patients. I was there for 34 years and by the time that I left I knew most of them by Christian name. You get a feel for your patients, what their values are, what lifestyle they have, who their relationships are, and the relationships that they have with all their family. When you are looking at their best interests, it may be making a number of clearly clinical decisions, but to do that in isolation of their other relationships as well would be constricting their best interests to just the medical model. What we were getting at was looking at a wider concept, which may involve other people as well and their interests, because of their relationship with the person.

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Q13  Lord Faulks: I would like to ask, if I may, about withdrawal of treatment and the application of the Mental Capacity Act in circumstances where treatment is withdrawn; in particular, DNACPR notices, which, of course, are extremely difficult, even if the patient has capacity, let alone if there are some doubts about capacity. I wondered if any of you had experience of this and whether you feel confident that the MCA is being applied appropriately in these delicate situations. Before you answer, I should declare an interest that I am involved in a case going through the courts, as a barrister, about the DNACPR notices.

Dr Calland: Shall I kick off? As I understand it, the primary criterion for looking at whether one would start CPR or not would be whether it was going to be successful. If you have a patient with extremely severe heart failure, who has been literally chugging along for months and months, is severely breathless and severely swollen, and who is coming to the end of their treatment path, it is highly unlikely that CPR would be successful. Even if it were, it probably would not be for any significant length of time—a matter of hours or whatever—in which case it would be arguably lacking dignity and everything else that goes with it. Primarily, that must be the first point.

Where we have got into so much difficulty with “do not resuscitate” orders is around communication. There has been, for all sorts of different reasons, a failure of good communication, so that maybe the patient themselves, if they have capacity, or their relatives, if the patient does not have capacity, are aware that such orders are placed on people and why. There should be a debate about it, because it used to occur in the nursing home that we looked after and, of course, it was quite difficult sometimes, because you would have people who were absolutely at the end of their life, but their relatives had not got there. They had not worked out that this was where their mother or their father was, so talking to them about putting a “do not resuscitate” order on equated to them as, “So, you are going to let gran die, are you?” or “You are going to kill gran off”, which is very difficult. To some degree, the difficulty around this area is nothing to do with the legislation; it is to do with the mismatch between people’s expectations, really.

Dr Apakama: We only do “do not attempt CPR” on occasions where someone has an advanced decision, but again that is hardly ever available. For every patient who comes to the emergency department and requires resuscitation, we would have to make that decision based on the circumstances, which will include the prognosis at the time and the comorbidity, if we are able to get that information. We usually make this decision with the specialty team. The “do not attempt CPR” order is usually made independently of the decision not to give other treatments, so it is hardly done. It might be started in the emergency department, but it is usually done by the specialty teams.

Lord Faulks: Do you mean that it is a multidisciplinary decision, very often, if you can get information from different disciplines about morbidity?

Dr Apakama: Yes. When they come in, we would start resuscitation until we obtain information, either from the ambulance crew or relatives who have come along with them. Halfway through we might decide, for futility reasons, to discontinue CPR. Alternatively, if you have successfully resuscitated the first time, you have to consider so
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many factors regarding whether, if the patient arrests again, you are going to attempt resuscitation. This decision is usually made after we have considered all relevant factors. If we do not have all relevant factors, we have to base it on the prognosis and the past medical history, which is usually available on the hospital computer system.

Lord Faulks: Sorry, just one more thing about that: I understand exactly what you say about the consideration, but I am not quite sure where the patient comes in on this, if, indeed, they do. You are making a decision as to whether you think it is appropriate to, for example, give CPR once you have done it once, in view of the overall prognosis. But will you be consulting and communicating with the patient and, perhaps, his or her family, or not?

Dr Apakama: Such patients usually do not have capacity. If we are able to consult the family, we will definitely do so. However, most of the time they are brought in by the ambulance crew. We try as much as we can to contact the relatives. However, these patients do not usually have capacity at that time.

Lord Faulks: So that may be emergency medicine. I suppose that in neurocritical care or something it might be rather different.

Dr Apakama: That would be different.

Professor Howe: In general practice, the usual scenario, if we are involved, would be a patient appearing to express a wish to create a DNACPR order. That is something that we would listen to, professionally, if that was what people wanted to discuss.

Also, the thesis of my young colleague, Dr Benedict Hayhoe, is predominantly around advanced care planning, and it may be of interest to the Committee that his respondents were much less confident about the right way to go about the details of an advanced care plan—not so much the decision, the implications, the understanding and the retaining of information but the formal expression of it in a way that would carry between agencies. I think this is where changes in the legislation—the shift from enduring power of attorney to lasting power of attorney and, perhaps, the societal context of the debate around assisted dying and the Liverpool care pathway—are somewhat unnerving both the public and their professional helpers around how to get that right.

I am sure that this is a wider issue than just our college, which would not be involved in the way that you have just discussed. It is more about, when patients come to us and they really do persistently want to make an advance care plan, whether we are able to do it in a way that helps and whether that constitutes core business, because that is also time-consuming. If you have to do formal documentation, there is a whole complexity there. I have just made LPAs for my family, and it was very expensive. I do not know how many people in the general population will go there. That is quite a big societal debate.

Q14 Lord Swinfen: I will change the subject to the deprivation of liberty, and it is to all of you. We heard from the College of Emergency Medicine a concern regarding where a restriction of liberty becomes a deprivation. Are you all confident that the
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DoLS are applied where this line is crossed? If not, would a definition be sufficient to address this? Do you, by any chance, have a definition up your sleeve?

**Dr Chalmers:** This is something that has interested me greatly. I do not think that a definition is possible, nor would I argue that it is necessarily desirable. First, I think that the definition of what constitutes a deprivation of liberty under the European Convention view is very much more holistic than the view that we would take with the Mental Health Act, where the paradigm is the patient objecting, “Let me out of this false imprisonment”. There is very much a bricks-and-mortar view of deprivation of liberty under the Mental Health Act, if I can caricature it in that way. As I understand it, the courts have taken a much broader view about the expression of personal liberty. It can be, “I am objecting to being here. Do not lock me up”, but it is also, “Let me see my family. Let me have choice in as much as I can.” That is an incredibly valuable position to take if we are going to protect the rights of very vulnerable people because, essentially, we are thinking about people who are in care homes where they may stay for a very long time rather than in psychiatric hospitals. It is hard to capture that richness in a simple sound-bite and I do not think it is going to help people.

There are pointers. There is a lot said about the Deprivation of Liberty Safeguards: that they are bureaucratic and that they are the wrong thing. There is a lot of negative press. However, my experience has been, on the ground, that when it works well it can promote autonomy and enhance people’s experience of being in a care setting. I do think we should not lose sight of the positive aspects. There are things that need to be changed. However, I will not digress on that.

I do not think we can have a definition. It would be helpful to my colleagues in A&E, who do not think about these things in such detail as psychiatrists do. However, some of the pointers that we already have about “not free to go”, and staff exercising full or complete and effective control, are relatively understandable to most people. For A&E, the code of practice, if that could be enhanced, would be helpful, because there is an issue about the intensity and duration of that restriction that is now amounting to a deprivation of liberty. There could be guidance in the code to say, “In these common situations, it is viewed that this is not a deprivation of liberty.” Rather than a definition, then, the guidance should come through the code with case examples of the common problems. That is my starter for 10 on that one.

**Dr Apakama:** I do agree with that. It might be difficult to define deprivation of liberty but, like Dr Chalmers said, it might be helpful to have some specific examples of care or action that would amount to deprivation of liberty. What we have in the code of practice is a list of factors that existed in the Bournewood case. Our staff are worried that it also states in the code of practice that accumulation of these minor actions might amount to deprivation of liberty. However, in the emergency department we take measures to avoid crossing that line. One of them is to consider all the options and apply the least restrictive one. Secondly, we try very hard to review the care plan regularly.

**Dr Chalmers:** It would be helpful—and I know that the Mental Health Act code of practice is currently being revised—if we begin to think about what deprivation of liberty means in different settings. The three key settings for medical professionals would be a psychiatric hospital, a general hospital and a care home setting. If we
distinguish between these three settings and look to common case examples, because our colleagues feed these back to us regularly, we could get a better understanding. With better understanding, we protect people’s rights better.

Baroness Barker: In a general hospital, would you make a distinction between the emergency department and the rest of the hospital?

Dr Chalmers: Yes. I think that would be helpful

Dr Apakama: Yes.

Dr Calland: It is extremely difficult, but deciding which area or category of deprivation one is in would be helpful. Certainly, in the care home I used to look after, there was a lock on the door so people could not get out. It was a key/number thing, which was quite appropriate, in a way, for some of the inmates, because they used to go wandering off. That is, obviously, extremely difficult. There was a deprivation of liberty, I suppose, but there was a balance between that and suddenly having somebody disappearing off into the countryside, probably in the woods that were surrounding the building, which could have been very difficult for them.

There is also an issue about general hospital: very elderly people being in hospital who are probably there awaiting some sort of assessment or waiting for their community services to kick into action so they can go home. I suspect there are a huge number of people kept in hospital who are told, “You cannot go home yet because you do not have a rail up the stairs” or whatever. Whether that would fall into the category of deprivation of liberty, I do not know. If you talk to hospital management, there are plenty of people in hospital who are ready to go home but cannot go home because they have not got the facilities. Nobody is prepared to take the risk of them going home without their facilities. I have no evidence about the size of that problem.

Lord Swinfen: I assume that you would include sufficient care, in the way of individuals to care for people, as well as the aids that they require.

Dr Calland: Exactly. It is the whole community package. Because of the pressure on community service budgets, there are people in hospital—the hospitals constantly moan about this—who they cannot get out, either into care homes or home, because the community system has not kicked into action. They are effectively advised that they stay in hospital.

Q15 Baroness Browning: When Dr Chalmers mentioned her three settings, in the back of my mind I immediately hoped you were going to mention one which you did not mention—there is always a difficulty with these things—and that is people who are mentally ill and are detained in police station cells, sometimes overnight. It is a very common occurrence, far too common, and something that desperately needs to be addressed. There is no doubt about it that somebody who has been locked into a police station cell has definitely had a deprivation of liberty. I just worry about starting to categorise different situations, because that would have almost been at the top of my list.
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**Dr Chalmers**: They would have to be there with lawful reason, and I think you are, perhaps, referring to people who end up in police cells instead of hospital places of safety.

**Baroness Browning**: Exactly.

**Dr Chalmers**: Their detention is legitimised by Section 136 of the Mental Health Act, so their rights are protected but, as the College has repeatedly stated, the place of safety in a custody suite should only be used in exceptional circumstances. The College are working very closely with the Department of Health and the Home Office to try and improve this.

**Baroness Browning**: I hope you are making some progress on it.

**Dr Chalmers**: There are the nine pilot projects of nurses working alongside police officers in what has been known as the street triage projects. They have just been rolled out recently. We do not yet know if they will make a difference. My aim would be to reduce the numbers of Section 136, whether detention to police custody or a hospital place of safety, by people being able to access crisis care earlier in the pathway. For the purposes of my anguishing about the Deprivation of Liberty Safeguards, as part of the MCA, I think my three settings do pertain.

**Q16 Baroness Andrews**: I am going to take you back to a couple of things that you have already touched on very briefly. Professor Howe, you mentioned that there was a possibility of the GP training being extended from three to four years. We have been talking a lot about how to introduce, in the medical humanities, a culture where the young doctor is trained, not least in the complexities of mental capacity and mental health at an early stage. Do you think that that will happen? Will it, for example, help that young doctor who has done such interesting work on advanced decisions to feel that when he is qualified, he will have more grip on some of these issues, particularly in relation to advanced decisions? This is the broader contextual question. We have had evidence from quite a few people, including the carers’ organisations, who do feel that more attention needs to be paid to their difficulties in understanding their rights and access to the Mental Capacity Act. There is then the even wider question of what role the GP has in making sure that all the people on your list are aware that there is a right for them to make an advance direction to refuse treatment. These are very big questions that unfold one into the other, I am afraid. This has been emerging in evidence.

**Professor Howe**: We have already had the educational case, with the full revised curriculum accepted in principle. The question now is whether enhanced training will be financed. If it is, then the commitment is absolute. What I have in front of me says, “Part of the advanced training will involve further measures to help to train incoming GPs to effectively communicate with patients with communication difficulties, involve carers, relatives and friends, within the bounds of confidentiality, to develop professional judgment around lack of capacity and long-term care planning.” Is our revised curriculum aiming for this enhanced training? The answer is yes.

In fact, my doctoral student is already qualified, but I am sure that, had he come out at four years instead of three, he would have been more confident and had higher

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professional competencies in this area. I have said this before, but some of the examples that trouble people who have given witness to you might stem not from the group who are newly qualified, but from the older generation like me. Our other challenge, through guidance, master classes, training and e-learning communications, is to make sure that GPs who are already qualified keep this as much at the front of their minds as they need to. That is part of our College’s mission, as I have said.

As for the carers’ work with the Princess Royal Trust, again, we identified, created and leapt at the possibility of doing that because we saw a need and heard, as a college, some of the needs of the people that you are addressing. However, to make sure that every practice has good practice with carers’ identification and support is still a mission that we have to keep along with.

Q17 Baroness Andrews: Indeed. In an earlier exchange, you raised a question, “Does information about advance decision constitute our core business?” I think it is a very interesting and important question but if it is not the core business of the GP—and it is quite difficult to know at which point you take people’s sides and say, “I think we had better have a discussion about your advance directions”—whose core business is it?

Professor Howe: Again, in Dr Hayhoe’s thesis, this was a research question. What he heard was not that colleagues thought it was not part of their remit, but they were under-confident and, indeed, somewhat unclear about where the role of the GP and having that discussion sat alongside the formal documentation and legal expectations. It may be that advice could be forthcoming for my discipline and for others on that subject, if that makes sense. Indeed, when I see patients who are progressing, for example, with dementia over time, it is always at the front of my mind that I must make open to them the possibility of having that discussion with me. If they, or their carer, cue into it, I must go there. However, when one gets to a certain point and thinks, “I still have nothing about what they want to do with advance care planning and I really must raise it”—and I have personally done that too—this is where the field is somewhat less clear than the MCA, because this is implicit, if I have understood it correctly, in the current legislation. It may be something, again, that we need to look at, at a cross-sectoral level.

Baroness Andrews: Does your doctoral student have a question that would enable us to tell whether people were, as it were, volunteering to ask the GP whether it was appropriate for them to discuss it with him, even if they were perfectly well? Do we know anything about the demography of the ask?

Professor Howe: We do, although it was only with a small sample. One of the interview questions was, “How common is this view in your practice?” In fact, I think it was the opening question. Perhaps, once he has had his examination, we could send you the executive summary. The GPs who were responding were starting with those examples, some of whom were very competent, sentient people saying, “In 20 years’ time, I want this.”

Professor Bailey: You mention the wider context. There is, perhaps, almost a missing person around this table: is there a public health role here? Within the Academy, we are looking at a whole stream of work around ageing well. Within that, you would want to consider and have public awareness about the Mental Capacity Act and an advance

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decision to refuse treatment. This could involve each and every one of us around this room, at any point in time. Therefore, public health needs to be part of this discussion and debate.

Q18 Baroness Browning: This is a question to the BMA—for Dr Calland, I suspect. It is about your evidence and the role of IMCAs. You have suggested that they are being overused and, at one point in the evidence, almost that they are being called in for trivial matters that exceed their remit, perhaps. I have to say, that is in contrast to other evidence, particularly from the social workers when we took evidence from them. I wonder if you can elaborate on your concerns and outline what you think the appropriate limits of an IMCA should be.

Dr Calland: We reported this issue, because it has been raised in telephone calls from our members to our ethics department, so it is anecdotal evidence. I do not think it is widespread around the country. There probably is a degree of confusion around at what level the IMCA should be involved.

I will use a simple example. If there is a decision to be made about whether to treat a particular patient at the end of their life with an antibiotic for a chest infection, and they have no relatives, that would be a big decision to make. An IMCA may well be seriously appropriate for that. However, if the choice of antibiotic was between amoxicillin and oxytetracycline, would the IMCA need to be involved in that sort of decision, which is much more of a clinical decision? What I am trying to do in that example is to show that there is a different level of seriousness of the clinical decision. Some doctors have found that some IMCAs have wanted to be involved in the clinical decisions—like which antibiotic, as well as the much more important and appropriate decisions of whether we start the treatment or not.

Baroness Browning: The IMCA, in the scenario you have just painted—the choice of the two antibiotics—would quite naturally ask the questions, would they not? They would want to know which antibiotic, and presumably—as if the patient was sitting there—the doctor would explain the difference between the two.

Dr Calland: Yes. I am using that as an example. Although we put this issue in our evidence, because it has been raised with us, I do not think we are sitting there worrying about it hugely. I can well understand that there are other people who have had different experiences: that IMCAs have not been involved when, maybe, they should have been. I am not going to die in a ditch for pressing this one.

Baroness Browning: Presumably, in some cases, it is not just a matter of a clinician’s decision; it is a multi-agency scenario where there may be other things associated with the decision that might appear to be trivial but are, in fact, part of the whole. I just noticed that the word “trivial” was used. You say, “Otherwise there is a risk of enrolling IMCAs for large numbers of trivial decisions.” If I just put myself as the patient, and I lose capacity, I want whoever, whether it is an IMCA, a relative or whoever, to be asking all the pertinent questions.

Dr Calland: You are absolutely right, and maybe the way that is worded is a fine example of medical paternalism.

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Q19 Baroness Browning: Could I just ask you one question, if I may? I have asked it of other people who have given us evidence. When the original Act was going through the House as a Bill and we had the pre-legislative scrutiny, there was quite a lot of discussion about the need for people who have lost capacity, or have fluctuating capacity, to be able to make unwise choices, on the basis that all of us, even those of us with capacity, from time to time, make unwise choices. Has your experience now of the Act, in practice, made you wonder whether that was the right approach?

Dr Calland: As I understand it, one of the underlying principles of the Act is to enhance autonomy on behalf of the patient. As you have just said, everybody has the right to make a decision, however unwise it may be. We are getting back into risking even more medical paternalism if we do not emphasise that particular right. As far as I am concerned, as a citizen rather than a doctor, I would want my wishes to make an unwise decision to be carried forward. That is my personal opinion.

The Chairman: I wonder if Professor Howe could write to us on one matter. I suspect that you may have the information. Could you tell us: how many general practitioners there are in England and Wales; how many are members of the Royal College; how many practices there are in England and Wales and how many of these practices have a partner who is a member of the Royal College?

Professor Howe: I can notify you with that, yes.

The Chairman: I think it would be useful. Thank you very much indeed for all your evidence today. We are extremely grateful to each and every one of you.
Advocacy in Action – Written evidence

Advocacy in Action is a charitable trust corporation specialising in providing personal financial management to vulnerable people under Power of Attorney or Court of Protection Order since 2002. The charity is a Court of Protection panel deputy, but as a trust corporation is not permitted to take Health and Welfare Deputyship. The charity provided a general advocacy service to vulnerable people from 1999 to 2012.

Overview and context

1. We believe that the MCA has brought about significant improvement in enabling vulnerable people to be assisted in managing their financial affairs, although much remains to be achieved. Some areas for improvement are identified below.
2. Areas of the MCA which would benefit from amendment are identified at the end and after specific questions have been addressed.
3. The principles and definitions of capacity and best interests have provided a valuable framework for assessment and practice.

Implementation

4. We most often observe the 5 principles being put into practice by registered social workers, some health professionals and staff from the voluntary sector working in this field. Where members of any profession fully understand the 5 principles there is a satisfactory balance between enablement and protection, otherwise we observe an expectation that people without capacity are given guidance they cannot remember or a culture of professionals making decisions on behalf of people, without applying the best interests principles.
5. We are not aware of the details of the Government’s implementation plan other than provision for the training of IMCAs and observe that sustainable change appears to be achievable in social services and relevant specialist services in health (e.g. psychiatric services for older people) but not in other areas.
6. We observe that the MCA may be known about but is not widely understood or implemented in a number of sectors. We have seen no evidence of understanding or implementation in the areas of domiciliary social care, housing support services, hospital staff (with a few exceptions) and we observe that frontline staff in banks have a very limited understanding of the mental capacity of an individual and appear to lack guidance on how to deal with problems arising from lack of capacity. We also observe that many solicitors do not have an adequate understanding of the MCA and its implementation unless specialising in Wills, Trusts and Probate or Court of Protection work. Banks now claim to have comprehensive procedures in place to deal with Lasting Powers of Attorney and Deputyship orders, but may prevent a person retaining capacity from dealing with their own affairs, or may allow a person lacking capacity to be financially abused because the person appears to be compliant. The problem here appears to centre around the timing of the registration of the LPA. Under the old EPAs powers were not registered until the done had reason to believe that the

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donor was becoming mentally incapable of managing his affairs. With the LPA registration takes place at the outset, and while this has advantages, there is no procedure for notifying the OPG when the done has reason to believe that the donor is losing mental capacity.

7. We observe that the MCA appears not to be widely known about or understood by people who may wish to make provision for eventual loss of capacity or the friends, relatives and carers of those losing capacity. In most cases crisis point is reached and people find out about the Act and its provisions from social services, professionals in care and nursing homes or the specialist medical team (psychiatric services for older people, medical staff dealing with brain injury, etc). We believe that most informal carers do not understand the Act sufficiently and therefore do not derive reassurance or protection from it, either for themselves or those for whom they care. We regularly receive enquiries from family members, referred to us by professionals familiar with our work, for advice and guidance when an individual is losing or has lost mental capacity.

When properly implemented and with support from informed professionals (from statutory or voluntary services), we observe that the right balance between protection of the carer and protection of the individual can be achieved.

8. We observe the most marked change in culture in social services, and some care and nursing homes. We observe an absence of cultural change in domiciliary care services (having been informed by one manager at a safeguarding meeting that the MCA was nothing to do with them). We are concerned that staff of Housing Associations that we work with, who provide support for individuals with learning disabilities, appear to manage the services and the funds of their clients for the convenience of the organisation which makes decision about what is best for all. Their discussion with their clients does not follow ‘best interests’ practice, we are told that staff offer a service, the clients agree, and we are then asked to fund this (as deputy). We are concerned that the holding of appointeeship in respect of benefits for many clients, and creates a conflict of interest. We are also concerned that relatives of any of these clients who hold appointeeship do not have any understanding of the MCA, and therefore just agree to pay whatever is requested.

9. We have no evidence as to whether the provisions of the MCA affect some groups disproportionately. However we are aware from work we have previously done that individuals lacking mental capacity tend to be ‘hidden’ by their families in some ethnic groups. It seems likely that, where this situation applies, the principles of the Act are not applied.

Decision making

10. We observe that those directly affected by the MCA are being enabled and supported to make decisions for themselves to a greater degree than in the past, where informed professionals are involved in supporting the individual (and their carer or relatives if this applies). We do not observe that the means (general authority, Lasting Power of Attorney, deputyship or Court of Protection) makes the difference at this stage, but rather the influence and

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Advocacy in Action – Written evidence

guidance of a trained professional with a good understanding of the MCA and its principles.

11. We have little evidence that advance decisions to refuse treatment are being made. We have had one situation where an advance decision was made available to medical staff and was followed.

12. We are aware of situations in which the MCA has fostered appropriate involvement of carers and families in decision-making. Many of our clients have no family members able to be involved in decision-making.

13. We observe that the role of the Independent Mental Capacity Advocate has had considerable success in providing a voice for clients and an additional safeguard against abuse and exploitation for those who have no-one to speak on their behalf. However we note that IMCAs are often working under great time pressure, and may not have time to get to know their client well enough. This can occur particularly when a decision is about place of residence. The IMCA may not have sufficient time (or possibly appropriate training) to establish whether a client wishing to go home still has a sufficient understanding of ‘home’. In some cases ‘home’ is back to parents who have, in fact, died many years earlier, or to a home which only exists in the individual’s imagination. This can be exacerbated where the individual has communication difficulties such as expressive and/or receptive dysphasia following a stroke, or the individual has learning disabilities or mental health issues.

14. We are unable to comment on the level of referrals to IMCAs.

15. In our dealings with IMCAs, we are aware of a number of circumstances where the service may be inadequately resourced and/or staff are insufficiently skilled to assist effectively in supported decision making for people lacking capacity.

Deprivation of Liberty Safeguards

16. We have insufficient experience of Deprivation of Liberty Safeguards (DoLS) to comment.

17. As above.

The Court of Protection and the Office of the Public Guardian

18. We have noted above that the MCA is not widely understood, and therefore believe that the Court of Protection and the Office of the Public Guardian (OPG) are not sufficiently understood and are usually accessible only with help from a trained professional – social worker, medical staff, solicitor or voluntary sector professional. Unfortunately we have a number of examples of excessive delay at the Court of Protection because papers have been lost. We also have a recent example where we believe that the OPG either did not apply section 13 of the MCA correctly, or there is lack of communication between sections of the OPG. In this example we have now applied to the Court of Protection for the initial decision of the OPG to be reversed, and are supported in this by the OPG compliance unit.

19. As a trust corporation we can only take Lasting Power of Attorney for Finance and Property matters, and therefore cannot comment on matters of

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personal care and welfare. We have been advised by clients that a number of high street solicitors refuse to help clients with LPA, where they would previously have assisted with an Enduring Power of Attorney. This reduces the number of solicitors available to help, but probably gives access to solicitors who have a better understanding of the MCA.

20. Regarding costs, as there are remission and exemption provision in respect of fees for registering an LPA or Application to the Court of Protection, we do not believe this is a problem. The problem lies in the cost of solicitors services in making and registering an LPA or in applying to the Court of Protection. The general public will usually instruct a solicitor in these matters. Only time will tell if the development of an online application for an LPA will have any impact. Some people are able to complete the necessary forms and procedures without involving a solicitor, and, as a small charity, we have been able to assist a few people with application to the Court of Protection.

21. We are not aware of any legal aid being available to provide access to legal services in registering an LPA or application to the Court of Protection.

Regulation

22. We believe that the Care Quality Commission should be inspecting on MCA standards and training provision in MCA in all the areas for which it is responsible. We have particular concerns about the understanding and training of domiciliary care staff.

23. Mental incapacity affects all the aspects of the life of any individual incapacitated. It is important that all regulators, including health and social care, should be fully aware of the MCA and providing regulation for professionals dealing with people lacking capacity. This should include, if possible, solicitors and banking services. We are not aware of any regulation for ‘support’ such as that provided through Housing Associations, and believe that this could usefully be considered.

24. We are aware that mental health professionals working with adults have a poor understanding of the MCA. We have seen one situation where the MCA should have been used to deal with a situation, and the Mental Health Act was used instead. We hope this was an isolated example!

Devolved administrations and international context

We have no experience in these areas to enable us to comment.

Registration of the LPA and implementation in practice

The problem is that professionals, especially banks, where front-line staff have little or no understanding of the MCA in its totality may misunderstand the LPA. It can be interpreted as was the EPA, with decision and control of affairs making being refused to the donor because the LPA has been registered and only made available to the attorney. Alternatively services may continue to be made available to the donor after s/he has lost capacity, thus undermining the role of the attorney. Either of these situations can create problems for donor and/or attorney, and can also facilitate financial abuse of the donor.

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We believe the current registration process should be a recording process only, and the LPA should then be returned for formal registration when the donor loses capacity to make financial decisions? We understand that there will be additional administration involved in implementing such a system, but it would then be clear to those dealing professionally with the donor whether or not they are dealing with a person who has capacity to make financial decisions.

If this is not feasible, can consideration be given to alternative ways of achieving clarity as to whether the donor of an LPA does or does not have capacity to make financial decision. The aim would be to achieve a better basic system so that, while recognising that decisions are time and decision specific, people are regularly assessed as to whether they still have capacity to manage their financial affairs.

This point may also be relevant to personal care and welfare, but we do not have experience to comment in that area.

**Access to advice and information on the MCA**

The requirement for advice and information always arises from recognition of a problem or potential problem. Confusion, especially in older people, is often caused by physical health problems and these must be checked first. However, if there are no identified physical health problems, then a form of dementia needs to be considered. We are aware that a lot of work has been done by the Alzheimers Society and others in helping people understand the support and care needed by those with dementia. We are also aware that the area of finance can often be overlooked. As long as the individual says ‘yes’ to paying a bill, they are deemed to have capacity, although they may be failing to deal with more complex financial responsibilities. While we know that a proportion of social services and health professionals understand the MCA, many do not. In particular, they tend not to understand what is involved in capacity to manage ones finances. We suggest that it would be helpful to identify and make readily available a list of people or organisations with expertise in loss of capacity over financial affairs, so that those needing advice and information can be referred direct to an expert. A referral, for instance, to social services will usually result in a social worker at the lowest level assessing needs. While this is appropriate in respect of care needs, this person rarely has the expertise to recognise the need to deal with financial matters. This can leave the client open to considerable and repeated financial abuse as well as neglect before the problem is recognised.

**Security bonds for Deputyship**

Regulation 37(3) of the Lasting Powers of Attorney, Enduring Powers of Attorney and Public Guardian Regulations 2007 ("the Regulations") S/ 2007 No 1253 provided, inter alia, that following the death of the patient a security bond would remain outstanding for a period of 7 years.

Every deputy has to take out a security bond. Professional deputies such as ourselves who handle many deputyships are usually granted a “bonding limit”. A bonding limit is the maximum value of security bonds that an insurer will allow a professional deputy to have outstanding at any one time. Once the patient has died there is quite rightly a run off period from the date of death of the patient but many of the bonds that are running off were taken out when the run off period was seven years and are still counted against
Advocacy in Action – Written evidence

the bonding limit, for that period. This could create a situation where new deputyship cannot be taken on because they are utilising headroom within the bonding limit and therefore might be against the potential patient’s best interests.

The Lasting Powers of Attorney Enduring Powers of Attorney and Public Guardian (Amendment) Regulations 2010 S/I 2010 No 1063 paragraph 4 helpfully reduced the run off period from the date of death of the patient to 2 years with effect from 1st May 2010 but has left two systems operating concurrently one with a run off period of 7 years from death and the other with a run off period of 2 years. From the point of view of the professional deputy this creates inefficiency and the continuance of the 7 year run off period wastes the Court’s time dealing with bond discharge applications which may be required to ensure that there is sufficient headroom within the bonding limit to facilitate the taking on of new cases.

It also means that contingent liabilities are remaining on insurance companies’ balance sheets longer than may be commercially necessary with the resultant impact on their capital ratios.

It seems to us that this issue can be simply dealt with by the wording of Regulation 37 paragraph 3a being amended to retrospectively shorten the run off period to cover the situation where patients had died prior to 1st May 2010.

It also seems to us that Paragraph 37 (3)(b) presents possible problems for executors of estates of deputies who die while still appointed. It is likely that should the security bond be claimed upon the insurer is likely to seek reimbursement for the estate of the deceased

a) How would this potential liability be reported to HMRC and how should it be treated for IHT purposes

b) Could the estate of the deceased deputy be finally administered while this potential liability remains outstanding

30 August 2013

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Advocacy Matters IMCA Service – Written evidence

2) The Code of practices are very useful in some aspects but were written prior to acts coming to effect therefore they could do with some revision. As the Act has been in force for some time now the Code of practices could be amended to reflect best practice as there is sometimes great variation in practices and the application of the Act’s in case law, particularly relating to DoLS, as the code of practice is vague in some respects.

Amendments may not be needed necessarily but clarity is often lacking. In our experience as IMCA’s there appears to be a lack of clarity around the interaction between the MCA and other aspects of law (e.g. capacity and tenancy, MHA). Professionals also appear to struggle to find guidance on how to deal with disputes amongst family/friends.

3) We feel the principles of the Act are completely appropriate; they are short and concise and easy to remember and refer to in day to day work as an IMCA. The definition of capacity gives us and other professionals a frame of reference without being overly prescriptive.

4) The extent of the implementation of the Act is still evolving. We find there is still sometimes a tendency for professionals to act in a protective manner being risk averse. Evidence around this may be best provided by decision makers/IMCA’s etc in a qualitative manner rather than quantitative. Generally the principle around the assumption of capacity is understood and the principle regarding unwise decisions appears to be respected. Good practice in this respect could be evidenced by IMCA casework. Principle 2 can sometimes be overlooked particularly in cases of people with learning disabilities and dementia; in our experience clients are not always provided suited to their means of communication and assessments are not always personalised such as conducting it over several visits or in a quiet place.

6) Among health professionals, particularly doctors/consultants, there appears to be a real inconsistency around the level of knowledge of the MCA and IMCA’s. In our experience doctors appear to be either very knowledgeable or have very little knowledge or recognition of the Act. We still frequently come across situations where doctors want a next of kin to consent to treatment on behalf of an individual that lacks capacity or where they are not happy to involve friends or extended relatives as they are not 'next of kin'.

Within our local authority, we feel knowledge of the Act is becoming more robust and widespread. Confidence appears to be an issue particularly for social workers assessing capacity; social care professionals appear to prefer to have health professionals (such as psychology services) assessing capacity around accommodation or finances. In private health and social care, we have found knowledge of the Act is very variable and is dependent on the provider and how much emphasis they have put on training in this area. We have noted that since the local authority took over from the PCT as the supervisory body for DoLS, there has been more consistency in DoLS referrals which was lacking previously. Now we feel the process is more cohesive and there is one point of contact making it easier to access paperwork and information.

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Advocacy Matters IMCA Service – Written evidence

In health and social care there appears to be a variation in attitudes towards who is appropriate to consult and the reasons why someone is considered inappropriate therefore more clarity in this respect may be beneficial.

In our experience we are often a first point of call in relation to enquiries around the MCA and other legal aspects that affect people who lack capacity to make decisions (such as regarding finances). We also have professionals from outside our local area making enquiries indicating that there may not be sufficient information available within the social care and health care settings.

7) In our experience, the Act is not widely known by non professionals and is often misunderstood. People’s perception can be based on scant reports in media and it seems only extreme cases are documented in the media. There does not appear to be a great deal of education about the Act and it’s use and safeguards for the general public. In our experience, people worry about who will be consulted, how decisions will be made, if there is hierarchy of who is next of kin, and who is responsible for making the decision (i.e. family/friends are not the decision makers).

Practitioners appear to be wary of going against a family wishes and as we have seen cases where a decision made by the court reflected the families interests more than the individuals interests, there needs to be more clarity in this respect. Mediation is not a realistic or timely solution as suggested in the CoP.

8) We feel the Act has created a change in the sense that more professionals appear to give regard to a person’s capacity, potentially meaning that people have greater control over some aspects of their life now. We feel this is likely to improve as professionals improve their knowledge of the MCA.

10) The provisions of an LPA seem to be generally misunderstood e.g. the different types of attorney, requirements to be registered with OPG. We feel the Court of Protection isn’t easy to access or understand even as an IMCA. The decisions/judgments/case law are very interesting to read when published but sometimes they appear to be at odds with what the MCA was trying to achieve.

11) We have not come across advance decisions very often; in our experience they have been made by people with very strong religious beliefs. We feel there should be more guidance about this and potentially they would be used more then.

13) We feel IMCA’s have provided a voice for people who lack capacity in our experience. An IMCA can be a good safeguard as we look to find a balance between professionals being overprotective and interfering in someone’s life whilst managing risk. In our experience, there has recently been an increase in referrals around changing accommodation for people largely based on cost e.g. large service re-provisions. The IMCA service have certainly ensured decisions reflect a person’s best interests rather than service level agendas and the wider economic picture. Involving an IMCA can also make professionals be more reflective about the decision making process.

14) According to the projections of our tender, our referrals have been lower than expected, particularly regarding serious medical treatment decisions. However referrals have been rising steadily since starting to deliver the service. Given the number of acute
hospitals in the area we work in, the number of treatment decisions are particularly lower than expected.

Local authorities are incredibly different from each other so it is sometimes unfair to compare them; the demographics of the population vary, the number of hospitals and the rural/urban make up of the area are all relevant to the variation. The commissioning of IMCA services in different regions also impacts referrals as some areas have not commissioned their IMCA service to do discretional decisions. Promotion of the MCA and IMCA is also varied in local authorities dependant on commissioning of that service

15) In our experience, we feel we are adequately resourced and skilled to provide the IMCA service. We have provided the service for a number of years and all IMCA’s have gained the NAQ with IMCA and DoLS specialist units. Anecdotally, professionals from other local authority areas have reported having difficulty obtaining an IMCA’s involvement in a case or accessing general information from the service in their area.

16) The principles of DoLS safeguards are perfectly appropriate however we have noticed great variation in what is considered to be a deprivation of liberty, there is therefore the potential for variation within a local authority area and between different areas dependant on the professionals involved in the authorisation process. Some BIA’s have reported case law in the matter doesn’t provide any further clarity. Whether a situation is authorised as a deprivation or not can therefore be quite subjective.

At times DoLS and COP decisions appear to focus more on the rights of a family member than the person who lacks capacity when restrictions are placed on contact or where the family is requesting the person be discharged to their care, e.g. the family members right to privacy and family life is the right being interfered with rather than the person who lacks capacity’s right to liberty.

17) Current authorisation/review/challenge processes are a good starting point but there is very little flexibility. In some cases the managing authority has not been responsible for creating the situation that has led to a person being deprived of their liberty (i.e. the person has been placed in care under an order of the Court or the LA has made an emergency decision) but the managing authority have to make the request for an authorisation. Sometimes they have insufficient evidence to justify the deprivation they are being asked to carry out. In these instances it appears it would make more sense for the decision maker to raise the authorisation rather than the managing authority.

The review process doesn’t appear to be very formalised. In our experience best interest meetings are not generally part of DoLS process but potentially could be beneficial, particularly if the person deprived requests the review. It would be a good opportunity to involve the person deprived if appropriate.

18) Unfortunately, our direct experience with the COP has been limited to four or five cases. There appears to be little information easily available about when to approach the court and what the expectations from the court hearing are; we are also mindful that we do not want to not be representing the people we are supporting and at the same time not wasting the time of the court. The COP or Official Solicitor do not appear to be particularly approachable as it is not easy to make contact or gain information from them. There appears to be reluctance from professionals to approach

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Advocacy Matters IMCA Service – Written evidence

COP due to the cost and it appears to be considered as only for ‘life or death’ situations.

19) In our experience LPA’s are very rare and professionals often appear to be unaware of how to clarify whether someone has an LPA, if it is valid, and how this impacts on who is responsible for making the decision. There also appears to be some confusion about how to register concerns about someone’s LPA.

20) Information around costs for approaching the court is very difficult to access particularly around potential means testing. In our experience we haven’t been able to be provided with information such as timescales and costs from the OPG and have had to wait for long periods to be able to make contact with someone from the court (very difficult to contact by telephone and emails sent to the enquiries email provided online have not been responded to).

23) We are aware that clinical governance in local hospitals have started to pay more attention to compliance with MCA, such looking at consent procedures. There does appear to be much more scope for regulatory bodies to look at compliance in health care settings. We have seen evidence of CQC giving regard to mental capacity and best interests in relation to care planning when carrying out inspections. There could be a case for the CQC having greater powers for monitoring the standards for MCA and DoLS.

24) In our experience the relationship between the MCA and MHA is not understood well at all. The MCA code of practice doesn’t give much clarity to the interaction between the MHA and MCA but the recent MHA code of practice gives more clarity on the interaction between the MCA and guardianship/CTO’s.

31 August 2013
Advocacy Support Cymru (ASC) – Written evidence

Overview and context

1. To what extent has the Mental Capacity Act 2005 (MCA) achieved its aims?

2. Which areas of the Act, if any, require amendment; and how?

*The role of the IMCA needs amending to allow IMCAs to work with all patients who are incapacitated whether they are befriended or not. This would act as a wider safeguard and remove the contentious referral system where a Decision maker feels that a family member is inappropriate to consult and yet IMCA gate keep and refuse the referral.*

*The language used to make referrals to IMCA needs to change. Instead if saying Decision makers "should" make referrals to IMCA it needs to say "must".*

3. At the core of the MCA are its principles and definitions of capacity and best interests. Are these appropriate?

Implementation

4. To what extent have the five principles of the MCA been implemented in frontline practice? What evidence is available to assess this? Is there a satisfactory balance between enablement and protection?

*The experience of advocacy is patients are deemed to lack capacity on "assumptions" of professionals because of a mental illness, deafness, appearance, age. The experience is that in the majority of cases the process of conducting a formal capacity assessment is not completed and not formally recorded. There is also very little evidence of practitioners trying other methods of communication to assist patients in regards to decision making.*

*The Advocacy experience is the most restrictive option is discussed and considered first. Many professionals do not consider what the risks are of returning to the person's own home, only that a care home is an easier option.*

5. How effective was the Government’s implementation plan? What measures were taken to ensure that professionals and families of those who lack capacity know about and act in accordance with the provisions of the MCA? Has it led to sustainable change?

*There are still large demographic areas where relevant professionals are working with incapacitated patients on a daily basis and yet have little or no knowledge of MCA 2005. This is true of families. There is no real evidence in practice that a sustainable change*.

6. Is the Act widely known and understood by professionals required to implement it?

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How does this differ across different sectors, such as health, social care, banking and others?

The general experience is Mental Health professionals often believe that Mental Capacity is not relevant to their practice and have little understanding of what capacity is. Some physical health providers do not feel capacity is relevant to their work and believe it "sits" in mental health. Often Social workers feel that if someone lacks capacity they need to be institutionalised for their own protection.

7. Is the Act widely known and understood by those who are directly affected by it and by their non-professional carers? To what extent does the Act provide protection and reassurance for informal carers? Has the right balance between struck between protection of the carer and protection of the individual lacking capacity?

Professionals have limited knowledge of the Act. In the Advocacy experience, the Act is known even less by Carers. The Act is used by Professionals negatively against Carers.

8. Has the Act ushered in the expected, or any, change in the culture of care?

In small pockets yes, but in most areas there is no evidence of any great change in the culture of care.

9. Is there any evidence that the provisions of the MCA affect some groups disproportionately? If so, what data exists to compare representation across different socio-economic groups, Black and Minority Ethnic groups, and gender?

Decision making

The MCA 2005 has been disproportionately used for young women who have been detained under the Mental Health Act 1983 and are having difficulties with the Family Division. Many women have had their children removed from their care and then are deemed to lack capacity to instruct a solicitor on assumptions that because they are mental ill they lack capacity.

10. Are those directly affected by the Act being enabled and supported to make decisions for themselves to a greater or lesser extent than they would have been in the past? Does the means by which the decision is made – ‘general authority’, Lasting Power of Attorney, deputyship, Court of Protection – affect the quality of decision making?

11. What evidence is there that advance decisions to refuse treatment are being made and followed?

12. Has the MCA fostered appropriate involvement of carers and families in decision making?

13. Has the role of the Independent Mental Capacity Advocate (IMCA) succeeded in providing a voice for clients and an additional safeguard against abuse and exploitation for those who have no-one to speak on their behalf?
14. Has the level of referrals to IMCAs met expectations? What are the reasons for the regional variations in the number of referrals?

Referrals to the IMCA service are not compulsory. So if Decision Makers are challenged by an IMCA they simply do not refer again. However, some Decision makers would like an IMCA for contentious cases where family are involved and not acting in P's "best interests" but are unable to access an IMCA due to the referral criteria IMCA service’s refusal.

15. Are IMCAs adequately resourced and skilled to assist in supported or substituted decision making for people lacking capacity? Many IMCAs do not have the resources or support to challenge decisions on behalf of their client.

Deprivation of Liberty Safeguards

16. Are the safeguards in the Deprivation of Liberty Safeguards (DoLS) adequate?

The Advocacy experience is that DOLs are being removed and not renewed. DOLs are being used significantly less; even where it clearly meets the threshold for a DOLs. The suspicion is that the DOLs are not being used so there are no safeguards in place and thus no opportunity to challenge Managing Authorities or Supervisory Bodies on behalf of P. Without a DOLs in place there is no route to challenge.

17. Are the processes for authorisation, review and challenge of DoLS sufficiently clear, accessible and timely?

Not really. Many professionals do not understand DOLS and as they are supposed to be the people who inform other of their rights, then this is difficult. One big example is the issue of who funds an appeal to the Court of Protection. The Act says that legal aid is available but most people do not know how to access this in practice.

The Court of Protection and the Office of the Public Guardian

18. Are the Court of Protection and the Office of the Public Guardian sufficiently understood and accessible to all? Are they operating effectively and successfully?

19. What has been the impact of the introduction of Lasting Powers of Attorney (LPA), especially with regard to decision making on matters of personal care and welfare?

20. What concerns, if any, are there regarding the costs associated with registering an LPA, or with making an application to the Court of Protection?

21. Is legal aid available and sufficient? What impact will the recent and proposed reforms to legal aid have?

Regulation

22. Is the role of the Care Quality Commission in inspecting on the MCA standards adequate and appropriate? Is there a case for additional powers?

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Advocacy Support Cymru (ASC) – Written evidence

23. Should other regulatory bodies, such as health and social care professional regulators, be acting in this area?

22 August 2013
About this call for evidence

The House of Lords has established a Select Committee on the Mental Capacity Act 2005. The terms of reference of the inquiry ask the Committee to “consider and report on the Mental Capacity Act 2005”. Age UK is pleased to have the opportunity to respond to the Committee’s call for evidence.

About Age UK

Age UK is a charity and a social enterprise driven by the needs and aspirations of people in later life. Our vision is a world in which older people flourish. Our mission is to improve the lives of older people, wherever they live.

We are a registered charity in the United Kingdom, formed in April 2010 as the new force combining Help the Aged and Age Concern. We have almost 120 years of combined history to draw on, bringing together talents, services and solutions to enrich the lives of people in later life.

Age UK provides information and advice to around 6 million people each year, runs public and parliamentary campaigns, provides training, and funds research exclusively focused on later life. We support and assist a network of 170 local Age UKs throughout England; the Age UK family also includes Age Scotland, Age Cymru and Age NI.

Please note this submission relates to our experience in England only.

1. Summary of key points

1.1. Age UK strongly supported the development and implementation of the Mental Capacity Act 2005 (MCA), however we are concerned that despite the clear link to human rights in the legislation, in practice, application of the MCA is often divorced from a rights based approach.

1.2. It is vital that the core principle of the presumption of capacity is adhered to when assessments of capacity are being made. Assumptions must not be made about lack of capacity to make a particular decision simply because someone is older, has dementia or is frail. It is of concern that professionals responsible for implementing the Act sometimes fail to appreciate that older people may regain capacity or have fluctuating capacity.

1.3. It is taking a long time for consideration of capacity to become embedded in day to day practice across the board in social care, health and the financial services sectors. A key barrier remains the very low level of awareness of the legislation among professionals, individuals and their families and carers.

1.4. Decision making involving older people often takes place in moments of crisis, under time pressure. In these circumstances, for example in hospital settings when treatment decisions need to be made urgently, it can be difficult for the MCA procedures to operate at the necessary pace. More effective publicity of advance
decision making and improved training for all health and social care professionals would facilitate more timely access to MCA procedures.

1.5. Age UK believes that it is very positive that the requirement to involve an advocate was enshrined in the MCA, however in practice the lack of timely access to effective advocacy remains a major barrier to achieving the aims of the legislation. Independent Mental Capacity Advocates (IMCAs) are currently under-utilised.

1.6. It should be viewed as positive that the number of Deprivation of Liberty Safeguards (DoLS) applications is rising, as it shows that more people are being afforded the protections that the legislation offers. However we believe that the figures may not accurately reflect the true need for DoLS protections among the older population.

1.7. Older people may face a number of barriers in seeking to access the Court of Protection (CoP) including high costs, lack of access to legal aid, travelling distances to the court and the length of proceedings.

1.8. There is a case for professional health and care regulators to take a greater role in relation to the MCA. More emphasis also needs to be placed on the role of employers who have a clear responsibility for ensuring that their staff are aware of and confident to use MCA procedures.

2. Overview and context

2.1. Older people who lack mental capacity for some decisions have little or no voice and are among the most excluded groups in society today. They are all too frequently deprived of their human rights to freedom, respect, equality, dignity, and autonomy. Age UK and its predecessor organisations Age Concern and Help the Aged have strongly supported the development and implementation of the MCA which is designed to protect these individuals and to safeguard their human rights.

2.2. We are concerned that despite the clear link to human rights in the legislation, in practice, application of the MCA is often divorced from a rights based approach, which takes as its starting point the individual’s right to be treated with dignity and respect for their right to autonomy. Practitioners frequently fail to ask themselves why they are applying the procedures mandated by the legislation and take instead a box-ticking approach. This means that application, for example of DoLS, is not closing the rights gap as effectively as it might and individuals do not feel that their rights to dignity and autonomy have been respected. In part this is also due to the lack of ability to challenge decision making easily, effectively and through channels other than the courts.

2.3. It is vital that the core principle of the presumption of capacity is adhered to when assessments of capacity are being made. In practice stereotyping often leads to assumptions being made about lack of capacity to make a particular decision simply because someone is older, has dementia or is frail.

2.4. In this context we are concerned that in practice there remains uncertainty about how to apply the two-stage functional test of capacity set out in sections 2 and 3 of the MCA. This confusion is perhaps to some extent inherent in the legislation as
the sequence of ‘mental impairment’ and then ‘inability to make a decision’ in 3(1) may appear to reverse that in 2(1) that a person is ‘unable to make a decision because of an impairment of, or a disturbance in the functioning of, the mind or brain’. The Code of Practice does explicitly state that the diagnostic question is ‘stage 1’ and the functional question is ‘stage 2’ but this has not always been how the test has been interpreted in the case law. Whilst the court’s approach in PC v City of York Council [2013] is arguably more person-centred and in the ‘spirit’ of the MCA than the Code’s, it demonstrates how confusion can arise for experienced MCA practitioners, let alone members of the public. Age UK recommends that the Code of Practice is updated to give greater clarity in this area.

2.5. In our experience anxiety, aggression and other ‘challenging behaviours’ in older people are often wrongly ascribed to a mental illness rather than to a potentially treatable physiological cause such as an infection or chronic pain that could be controlled. This can lead to wrongful determination of mental incapacity.

2.6. Professionals may also have a lack of appreciation that older people may regain capacity or have fluctuating capacity. This is particularly important where decisions are taken with long-term consequences, for example treatment decisions.

2.7. In practice the principle in the legislation that decisions are made in a way that is ‘less restrictive’ is frequently reinterpreted as requiring decision makers to take the ‘least restrictive’ option. This can cause confusion when actions under the MCA are being considered and may be especially problematic in a context in which decisions need to be taken that balance the rights of an individual with those of other people, for example staff and residents in a care home. Providing a range of statutory forms that local authorities and other decision makers could use rather than having to create their own, as exist within the context of the Mental Health Act 2007, may be one way to prevent the language being changed in this way.

3. Implementation

3.1. It is taking a long time for consideration of capacity to become embedded in day to day practice across the board in social care, health and the financial services sectors. A key barrier remains very low levels of awareness of the legislation among professionals, individuals and their families and carers.

3.2. Within older people’s social care we believe that implementation of the MCA has been inconsistent across the country, with people frequently failing to have their capacity assessed and relevant procedures not being followed when it would have been beneficial to do so. In other instances the legislation is being misused to support risk-adverse practice, as in the case of 82 year old Peggy Ross who was prevented by Cardiff Council, using DoLS, from going on a holiday cruise. The court decided that it was in the respondent’s best interests to go on the cruise, and also later decided that the respondent herself had capacity to decide whether or not to go.1

1 Cardiff Council v Peggy Ross (2011) COP 28/10/11 12063905v

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
3.3. In Age UK’s experience consideration of the MCA is all too often absent within health settings and questions of capacity frequently do not even enter the equation for older patients. The erratic implementation of the MCA reflects the variation in dementia care across the country. Part of the problem is due to a deep rooted lack of understanding of older people’s needs on the part of many working within health care. Trainee doctors for example spend very little time on older people’s wards as a core requirement of their training. Without this knowledge and understanding it is very hard for professionals to determine the role that the MCA provisions should be playing in older people’s care. In order to bring about the necessary culture shift much more needs to be done to embed knowledge about the care of older people, including mental capacity issues, into the training and assessment of health care professionals.

3.4. Age UK does not think that the MCA is as widely known and understood by retail bank and building society staff as it should be. Age UK continues to receive complaints from older people and their families about problems they experience when trying to manage their own accounts or an account on somebody else’s behalf. For example, we are aware of the case of an 86-year-old customer who was defrauded of £1,650 by a customer adviser with Halifax in Middlesbrough. The original court hearing was told that when she had first noticed the unauthorised withdrawals on her statement and had complained to the bank she had not been believed. Staff thought that she had forgotten to sign the withdrawal slips.  

3.5. Our sense, from the complaints that come through to us, is that financial institutions have the appropriate policies and procedures in place but that individual members of staff are not always aware of them. Our view is, therefore, that more efforts need to be made to make sure that all customer facing staff are trained and fully aware of the Act and what options are available to people trying to operate an account on somebody else’s behalf under their own policies and procedures.

3.6. We were pleased to contribute both to the guidance for banks and building societies and for consumers that was published in April of this year in collaboration with the British Bankers Association (BBA), Building Societies Association (BSA) and others.  Given that this guidance has only been available for a relatively short period of time it is impossible to say whether it has successfully improved practice amongst financial institutions, although we certainly hope that it will. We would expect that BSA and BBA will want to assess the impact that the guidance has in terms of raising awareness amongst industry staff.

3.7. In cases of financial abuse the MCA has helped those working in adult safeguarding to decide where to draw the line between what may be an unwise financial decision and what may be financial abuse. That is to say it can help them to determine where

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2 ‘Fraudster gets suspended sentence’ 20 Jan 2010, Money Marketing

3 BSA, BBA, OPG (April 2013) Guidance for people wanting to manage a bank account for someone else

4 BSA, BBA et al (April 2013) A framework for authorising people wanting to operate a bank account for someone else: Guidance for Banks and Building Societies

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it is necessary to intervene as it enables a specific test of capacity for certain financial transactions to be carried out. Although this can be problematic in terms of establishing retrospective capacity, it is helpful as a starting point for active cases of suspected financial abuse.

4. Decision making

4.1. Decision making involving older people often takes place in times of crisis, under time pressure. In these circumstances, for example in hospital settings when treatment decisions need to be made urgently, it can be difficult for the MCA procedures to operate at the necessary pace. Although this can be a sensitive subject, more effective publicity of advance decision making, including via GPs, social workers and solicitors could help to avoid this in some cases. Some organisations, including Age UK, are already doing this. Improved training for all health and social care professionals would also facilitate more timely access to MCA procedures.

4.2. It is enshrined within the MCA principles that people should not be presumed to lack capacity until all practicable steps have been taken to help them do so. We are concerned that this should be adhered to in situations where people could make decisions if they have appropriate support. For example it is proposed in the Care Bill, currently before Parliament that a suitable person could receive a personal budget on behalf of a person who does not have capacity to make decisions about their own care. We have called for the legislation to require that all practicable steps are taken to assist the person in managing their own budget before resorting to this option. This is likely to be a situation where access to advocacy is essential.

4.3. There is an information gap for families and carers about their potential responsibilities under the MCA when they, rather than a paid carer or professional, are decision makers. When required to act in this role they need to be able to access better information and guidance about the process of acting in an individual’s best interests.

4.4. Age UK believes that it is very positive that the requirement to involve an advocate was enshrined in the MCA, however in practice, the lack of timely access to effective advocacy remains a major barrier to achieving the aims of the legislation.

4.5. There are certain circumstances in which IMCAs have the potential to be especially beneficial to older people but they are currently under-utilised. These include providing advocacy in adult safeguarding cases and also acting as section 39D IMCAs, supporting the relevant person’s representative (RPR) in DoLS cases. In these situations the services of an IMCA are not routinely offered but in our view ought to be.

5. Deprivation of Liberty Safeguards

5.1. Recently published figures by the Health and Social Care Information Centre (HSCIC) have shown that there has been a year-on-year increase in the number of completed DoLS applications since their introduction in 2009/10. There were 11,887 applications in 2012/13, a 4% increase on the 11,382 applications in 2011/12. 55.1% of applications were authorised.
5.2. The majority (71%) of applications in 2012/13 were completed on behalf of people with mental health conditions, with dementia accounting for more than half (54%) of all applications made. As the HSCIC report goes on to point out this is likely to be related to the age profile of people who are subject to application for deprivation of liberty under DoLS (in 2012/13, 73% of applications related to people who were aged 65 and over). fifteen

5.3. It should be viewed as positive that the number of DOLS applications is rising, as it shows that more people are being afforded the protections that the legislation offers. However we believe that the figures may not accurately reflect the true need for DoLS protections among the older population. Given that the Alzheimer’s Society predicted that there were 636,099 people over the age of 65 living with dementia in the UK in 2012, of whom one third live in a care home, we think there may be many more older people who should be benefitting from them who are potentially being unlawfully deprived of their liberty. More research in this area is needed.

5.4. In its recent report on the implementation of the Mental Health Act 2007 the House of Commons Select Committee has stated that ‘implementation of DOLS has proved problematic, with wide variation in their use’. Age UK supports the Committee’s call for an urgent review of the use of DoLS to be presented to Parliament within 12 months.

5.5. A major problem in securing better implementation of DoLS is the difficulty of holding to account those Managing Authorities who fail to authorise and recognise deprivations of liberty. There have been very few successful legal challenges for Managing Authorities that we are aware of.

5.6. We are also sympathetic to the view that the complexity of the DoLS legislation is a barrier to implementation. The definition of what constitutes a deprivation of liberty and the potential overlap with mental health legislation are areas in which further guidance would be helpful.

5.7. Feedback from families and carers is that where DoLS are effectively used, they can be very positive. At its best the process allows for proper consideration by families, social workers and care providers of an individual’s right to autonomy and, as far as can be determined, their wishes.

6. The Court of Protection and the Office of the Public Guardian (OPG)

6.1. Older people may face a number of barriers in seeking to access CoP including high costs, lack of access to legal aid, travelling distances to the court and the length of proceedings. These may, in part at least, explain why rates of appeal to the CoP in best interests and DoLs cases remain worryingly low. Consideration should be given to developing less formal, more accessible complaints mechanisms that would...
allows individuals to challenge MCA decisions at a lower level before taking their case to the CoP.

6.2. The impact of the introduction of Lasting Powers of Attorney (LPA) has not been as significant as was predicted. In our experience awareness of LPAs among the general population is low and access to good quality information is not always readily available. In particular people are not aware of the two types of LPA. There appears to be a lack of understanding of the benefits of an early application as people are understandably reluctant to think about a future worst-case scenario and so put off applying.

6.3. Age UK has welcomed the opportunity to input our views into the OPG’s plans to introduce online applications for LPAs. We have made clear our view that while improving the process for online applications is welcome we would strongly be opposed to any move to scrap the hard copy version and promote sole use of the online version.

7. Regulation

7.1 The lead role of the Care Quality Commission (CQC) is clearly very important in overseeing the functioning of the MCA DoLs, but it is of concern that this is currently the only route via which the Government routinely can monitor the Act’s implementation. The level of knowledge and expertise in the MCA DoLs across all relevant parts of the CQC’s workforce is not clear.

7.2 There is a case for professional health and care regulators taking a greater role in relation to the MCA. For example there is reference to the Act included within the GMC’s ‘Good Medical Practice’ guidance but we would suggest that it could also be part of the revalidation process for doctors that is currently being proposed.

7.3 As mentioned above (para 3.5), it remains to be seen what impact the recently published framework for banks and building societies has and Age UK will continue to feed any complaints and concerns that we receive through to the BSA, BBA and Financial Conduct Authority (FCA). Whilst we supported the development of the guidance, if in the medium to longer term no evident improvement has been made in the practice of banks and building societies we do think that the BSA, BBA and FCA should consider taking further action to improve the customer experience.

7.4 More emphasis also needs to be placed on the role of employers who have a clear responsibility for ensuring that their staff are aware of and confident to use MCA procedures.

8 Other legislation and international context

8.1 In order to better protect the rights of older people who lack capacity it will be essential to ensure consistency between the well-being principles in the Care Bill currently before parliament, with the principles contained within the MCA. Crucially we believe the Care Bill offers an opportunity to provide this group with better access to independent advocacy. The Care Bill does not currently

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Age UK – Written evidence

refer to advocacy and there is little on how local authorities can be held to account for not complying with general duties such as provision of information and advice (which in our view should include advocacy). We believe that regulations should require local authorities to demonstrate that they have been through a process of considering how it will meet general duties. This would include a requirement that a local authority has considered likely demand for advocacy services.

8.2 Age UK has called for the Care Bill to include greater powers of entry where a third party is denying access to a person who is thought to be at risk of abuse. In some circumstances such a power might be necessary in order to establish whether the person has mental capacity.

8.3 It is very important to recognise that failures to properly carry out the legal requirements of the MCA will in many instances amount to violations of an individuals’ ECHR rights; including the right to private, home and family life (article 8), right to a fair trial (article 6), right to enjoyment of property (article 1, protocol 1), right to liberty (article 5), the right to life (article 2). In this context, it is especially concerning that certain groups of people receiving care services, who might fall under the remit of the MCA, are not currently directly protected under the Human Rights Act 1998. These include those who receive home care services provided by private and third sector organisations under a contract to the local authority and those who arrange and pay for their own care. Age UK is calling for an amendment to the Care Bill to designate all regulated care services as public bodies for the purposes of the HRA.

8.4 The parity principle in the Health and Social Care Act 2012 aims to promote greater equality of esteem between mental and physical health. For this to be realised for older people much greater emphasis needs to be placed on mental health. Currently mental health experience for older people is measured very poorly by the CQC, for example inpatient mental health experience is not captured at all. This is particularly important for those older people who are de facto deprived of their liberty in hospitals for long periods of time (sometimes even years) without any oversight. It is of grave concern that these individuals are ineligible for the potential safeguards of either DoLS or the Mental Health Act 2007. Clarification of the interface between the two pieces of legislation may assist in closing this protection gap.

8.5 With our partners Age International we have called on the Government to play a positive and active role in the United Nations Open-Ended Working Group on Ageing, encouraging the development of new human rights instruments for protecting the rights of older people, including the possibility of a new convention. We have called for such a convention to include a right to be recognised as a person who has rights under the law, to access the justice system just like everyone else and to make decisions, and get support to make those decisions, about their own life. This would include decisions about their health care, where they live, whether they work or not, how they spend their money, what they do with their own property, how they participate in family, social and public life, plans for care and support if they get ill in the future and where they would like to die.

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Age UK Cheshire Advocacy – Written evidence

My name is Lucy Welsh and I am a Senior Advocate at Age UK Cheshire. Our service provides advocacy support to any persons over the age of 65 years throughout East and West Cheshire. We are contracted by the Local Authorities to provide IMCA, IMCA DOLS, IMHA (Independent Mental Health Advocacy, a statutory provision under the Mental Health Act 1983 as amended in 2007) and general advocacy.

I am responding to the call for evidence on behalf of Age UK Cheshire advocacy, you will note that not all questions are relevant to the service we provide and so have not provided views on all questions.

Is the Act widely known and understood by professionals required to implement it? How does this differ across different sectors?

1.1 Understanding of the Mental Capacity Act ranges dramatically. Some Social Work teams can be very pro-active and positive about the Act and its principles, whereby other Social Work teams pay little attention to the fundamental principles of the Act such as least restrictive options and capacity assumed until proven otherwise.

1.2 In our experience Health Care professionals pay lesser attention to the Act than Local Authority Care Managers, in terms of instructing an IMCA.

1.3 There are issues over risk taking from decision makers. Rather than implement the lesser restrictive options when making decisions on behalf of people, some decision makers will opt for the option that is most risk averse, which in turn does not always mean the lesser restrictive alternative. There is undoubtedly a worry amongst some professionals that they will ultimately be responsible, as decision makers, for if something was to go wrong but a greater balance needs to be achieved between risk and restrictions that enables better consideration of all elements of the Act.

Has the role of the IMCA succeeded in providing a voice for clients and an additional safeguard against abuse and exploitation for those who have no one to speak on their behalf?

2.1 Generally, the IMCA role is an effective tool to additionally safeguard those vulnerable people in society who have no-one else to speak for them.

2.2 The effectiveness of the IMCA role is dependent on engagement and understanding from decision makers and referrers. IMCA’s can only act following a referral from another professional. It is clear that there is still a long way to go in terms of awareness raising and the duty imposed on decision makers to consult an IMCA in the circumstances prescribed in the Act.

2.3 When an IMCA is instructed it can have a positive effect on the outcome however it can be difficult (for reasons outlined below) to take forward concerns to the Court of Protection when a challenge against a Local Authority or Health trust is necessary.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Are the Court of Protection and the Office of the Public Guardian sufficiently understood and accessible to all? Are they operating effectively and successfully?

3.1 From an IMCA point of view, the restrictions to accessing the Court of Protection are based on the lack of legally aided funding for persons who are not subject to a deprivation of liberty authorisation. Under a DoLS any person is eligible for non means tested legal aid funding, however if a person is being treated under the Act for any other decisions then they are means tested for legal aid. This brings with it huge issues for IMCA’s who would likely act as litigation friend but are placed in a position whereby they have the personal responsibility of spending the money on legal costs of a person who is deemed to lack capacity.

3.2 There ought to better protections for IMCA’s acting as litigation friend. Currently there is a personal liability attached to the role, hence the likely reason as to why there is a lack of IMCA’s acting in this role.

3.3 There are lengthy delays in cases being heard in the Court of Protection due to the overwhelming number of cases awaiting appointment by the Official Solicitor. The IMCA services could reduce this delay by acting as litigation friend in more cases. However IMCA services are only funded by Local Authorities and contracts tend not to have the litigation friend role as part of the remit. The work of a litigation friend can be hugely time consuming (I have personal experience of this) and so the cost of this work would ultimately fall upon the organisation who is providing the IMCA service.

3.4 Provision could be considered for IMCA services, acting as litigation friend, to receive payment in lieu of the Official Solicitor in order to provide for the costs associated as acting as litigation friend. Obviously there would need to be checks and balances in place that would inhibit any vexatious claims from IMCA’s, who are generally not legally trained, but the issue is one that requires addressing and with some modifications could provide a solution to the delays caused by waiting for the appointment of the Official Solicitor.

3.5 The delays in Court of Protection hearings can be incredibly detrimental regarding an older person with dementia. Dementia is a deteriorating condition and the lack of timely decision making can have a negative impact on the persons quality of life. For example, once a person becomes institutionalised in a care home it becomes increasingly difficult, if not impossible, to reverse the effects of the loss of independence for if it is later decided that the person should return home.

2 September 2013
Age UK Devon – Written evidence

The numbers below in brackets refer to numbers given in HOL Call for Evidence.

1 (3) The definitions of capacity and best interests are excellent, appropriate and work well in practice.

2 (16) No: the DoLS sits in isolation from other services with no link to local care management or safeguarding. My team suggest that all persons detained under a DoLS standard authorisation should be allocated a care (or case) manager. There is also a problem in that Supervisory Bodies are only able to list DoLS “conditions” which bear on the Managing Authority. Often key actions which are needed lie outside the purview of the Managing Authority. If there were an allocated care or case manager then the SB could be allowed to list conditions which would be the responsibility of the care manager to carry out.

3 (17) No: these are far too complex and subject to subjective interpretation. Also the DoLS standard forms are very poor: they need review and simplification. They are repetitive, and key information (such as the length of authorisation of a SA, name of representative) is hard to find in the paperwork.

4 (18) Funding for Court of Protection and Official Solicitor seems to be inadequate, as cases take far too long to move through the system. The very long wait for the Official Solicitor to assess and allocate a case to a litigation friend is likely to disadvantage vulnerable people who do not have recourse to any alternative litigation friend. This means that in effect some of the most vulnerable clients may be deprived of their right to apply to Court for a ruling - eg to challenge a DoLS – in a timely way.

5 (18) It will often be in P’s best interests for an IMCA or Paid Representative to act as Litigation Friend: consideration should be given to making funding available to local authorities to fund this.

24 September 2013

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**Allied Professional Will Writers – Written evidence**

The Acts intention was (we assume) to **protect people** not to create jobs for bureaucrats and benefit lawyers. Our interest is in Lasting Powers of Attorney, which are troublesome and expensive beasts which need a swift and merciful death for the benefit of the public, though lawyers, bureaucrats and criminals may mourn their passing.

Why is a waiting period necessary at all, if each of the people involved writes a letter confirming they are happy to proceed – it isn’t as if crooks will include anyone who will object anyway? LPAs are often needed urgently, and we can’t think of a reason why their can’t be an emergency procedure taking no more than a week or two at most.

**MCA – The Prevention of Sound Legal Planning Act**

Life is full of constant changes, and sound legal planning dictates that everyone over 18 should have both types of lasting power of attorney in place, and (less importantly in most cases) a Last Will and testament.

At 18, parents and siblings would be the attorneys, but by 23 it will probably be life partner number 1 to be at least added as an attorney and included in the Will.

By 30 it will probably be life partner number 2 – and parents and siblings will be less of a concern so both LPAs will need changing again, as will the Will.

After regular annual reviews, the LPAs may stay unchanged until retirement (or may need changing several times especially for people who move frequently).

At retirement, the existing attorneys may be too close to your own age, and with people living into their 90s, then probably two more revisions at least will be needed to keep LPAs current until death.

So for sound legal planning, there will probably be seven changes in Lasting Powers of Attorney over a lifetime. Assuming just the OPG costs, that is a cost of £520 paid out seven times (at least) or £3,640. Let’s say you need advice on each occasion (as few people will carry out their own regular reviews) and the bill will exceed £12,000. So doing a proper job will cost the less well off a years salary. We’ve heard of £1,850 being charged for a single LPA, so some will be paying FAR more. And the cost doubles for a couple.

Going back to the days of the Enduing Power of Attorney, the equivalent cost would have been nothing at all, unless the EPA had to be registered through lack of capacity, and around half will never need to be registered. Not a perfect system, granted, but at least one which was accessible to ordinary people and which could readily be incorporated into sound Legal Planning. For the record, we used to charge £45 for an LPA and our cost for a pair of LPAs is £415 including the 24 pages of registration paperwork, plus 2 times £130 OPG fee = £675. That is a fifteen fold increase in costs on a one off basis, **and more than 100 times as expensive as an EPA** should 7 revisions be needed over a lifetime.
It may be argued that the poor earning £12,000 a year may have to pay less, but this exemption is of more use to the partners of the well off than the poor. The process of gaining remission of fees is a nightmare, with Government Departments refusing to supply the necessary information and the remissions team being hard to please. It would be interesting to know how many entitled people give up, and how many professionals even offer the remission facility knowing the extra work it will involve will invariably be significant.

**MCA – The Promotion of Fraud Act.**

For crooks, the MCA offers a welcome opportunity to rob old and or people of limited mental capacity with little fear of being caught.

All you need is some expertise in signatures or a couple of crooked friends. You don’t even need to meet the victim if you can gain access to their post.

The lunacy of not informing any member of the family has grounds in common sense – just carried way too far. There must be a REASON for not informing the family, and tighter controls over LPAs where the family is not informed. I wonder how many families will find out about the issue in future when their parents die owning nothing?

We are thinking of offering an audit service for annual accounts as even family are far from trustworthy, but maybe the OPG could conduct random audits with a requirement that bank statements and reasonable accounts are kept, though I hesitate to recommend even further bureaucratisation of the process.

**MCA – The OPG**

*It would perhaps be a thought to remind the OPG that their job is to help protect people rather than pick holes in their protection in order to create greater bureaucracy and leave people unprotected.*

**MCA – Deputyship**

We have little experience in this area, but great concerns about the costs and delays which would befall any member of the public whose LPA was rejected by the OPG for a minor infraction, or who couldn’t afford one in the first place.

The Acts intention was (we assume) to protect people rather than create jobs and benefit lawyers.

11 July 2013
Allied Services Trust – Written evidence

1. Allied Services Trust (AST) is a preventative charity, registered in the UK (1148194), founded having witnessed and being made aware of great need by those preparing for, and dealing with lack of capacity as defined in the Mental Capacity Act 2005 (MCA). The following information is submitted as evidence based on long standing work supporting large community sectors including the Armed Forces, Public Services and those planning for future Care. Our on-going cross discipline research is comprehensive; providing insight into all the contributory factors that are resulting in lack of engagement. AST are currently working on advanced research with specialist sectors including Southampton University (Russell Group) on a further research paper and literary review. Our continued strategy and engagement with major sectors, has addressed resolution in a proactive and preventative strategy.

2. The benefits of the MCA to safeguard mentally incapacitated individuals are worthy; however the Act has ability to produce a negative effect in the form of financial burden and hardship placed not only on individuals and their families, but third parties, charities and Government. As our population ages and survives severe life changing injury, degenerative illness, mental ill health and incapacity it is foreseeable that the negatives if not checked and addressed will continue to escalate.

3. Significant work with many groups has led to considerable breadth of insight for the AST Select Advisory Board (SAB). A major overview and response was submitted by AST to The Office of the Public Guardian (OPG) as part of the consultation on Digital Implementation in 2012. The OPG have acknowledged the need to assist those who do not have skill sets or facility to prepare an LPA themselves. The AST work in Awareness and Education has been positive in achieving success with all sectors and has proved a major contribution to engagement. The OPG Digital Transformation Program will enable far easier LPA creation opportunity. Their out of date IT has been a frustration to service delivery, and the OPG are keen to implement the program to empower individuals to prepare for possible lack of capacity. However, there has to be cognisance of the 18% of the population who are without IT capability.

4. Since 2007 a minimal amount of data has been gathered regarding LPA creation, administration, revocation etc. This has resulted in a significant lack of information to extrapolate, assimilate and rationalise trend and likely outcomes. AST identified the need for assimilation of data from all areas including end users, Government, Commercial and Third Sector. In the last 2 years their research has enabled preparation through preventative education and recognition of the facility needed to accommodate future needs for successful delivery.

5. The Court of Protection (COP) is being used as a court of everyday rather than of last resort, due mainly to total lack of preparation of an LPA by individuals. This has resulted in the system ‘clogging’ and significant delays which are costly, and not beneficial for cases that really do need COP decision.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
6. Costs incurred from the COP include application fees with annual supervision fees payable to the OPG, both of which are an added financial burden for those who have been caught out by lack of preparation. The COP prefer to appoint a professional deputy if the estate to be managed is a reasonable size. If a professional exceeds the fixed costs they are at liberty to have the bill assessed. This does put a safeguard in place with ‘fee ceilings’ for graded fee earners to restrict extravagant hourly rates, set by the Supreme Courts Cost Office (SCCO). However costs can still be considerable depending on the complexity of the case. The heart wrenching case histories that keep repeating, illustrate the often excessive cost implications that should never arise had there been a registered LPA in place.

7. For those who suffer trauma through injury, compensation supports deputyship administration costs following the litigation process. However, the numbers suffering mental incapacity from trauma are a minority to the many more who will suffer lack of mental capacity through debilitating illness and conditions such as dementia. They have no such third party consideration to support fees.

8. There is a severe cost being placed unwittingly upon those who have made a Professional Attorney Appointment (PAA). When an LPA is created, a clause details payments to be made to that professional. An LPA may not be required for many years, and in the intervening period the professional attorney’s charging structure, and the resulting cost implication may change and increase significantly. The length of the appointment will not be known in advance but it is foreseeable that with an ageing population surviving severe long term debilitating illness, injury, mental ill health and incapacity, administrations will be required for a considerable length of time (in some cases many years). How those professional fees are to be paid and sustained are not being considered in enough depth. It is foreseeable that depletion of assets due to PAAs resulting in financial hardship will increase. A professional is at liberty to revoke their appointment if their client cannot pay.

9. Revocation of an appointment be that lay or professional, once capacity of the donor has been lost will most likely require a deputy compounding and exacerbating cost and in some cases hardship. For those with depleted assets an appointee could be made, but who will act? How will they be paid?

10. Professional administrations are a ‘cash cow’ for the legal sector, Court of Protection work is a rapidly growing area. PAAs are a valuable income stream. There is no upper cap to the hourly rate charged. Unless specified within the LPA, the need to provide annual accounts or report to a third party is not required. The OPG does not require annual accounts or a report under an LPA administration. The OPG are only likely to investigate a case should concerns be reported.

11. The lack of awareness of the preventative benefit and indeed even the existence of an LPA in all sectors of society and at all levels is very concerning. To illustrate many of the elements, this particular example is of the Armed Forces Community (AFC), where an LPA is more important than most. One of the main contributory factors leading to the founding of AST was having had the opportunity to witness first hand and engage with Military units preparing to...
deploy. The almost total lack of knowledge and understanding regarding Lasting Powers of Attorney (LPA) was disturbing at all levels. This evidence was obtained whilst working from within the commercial legal sector, independently and within the third sector.

12. It appeared that at no point during the creation of the MCA was there any real engagement with the Ministry of Defence (MOD) to give input as to the likely effects and outcomes the Act would have on personnel. No consideration appears to have been given as to the likely 'blocks' to engagement to prepare for lack of capacity by this community. Blocks we have discovered and been made aware of are:

- **12.1 Lack of awareness:** The MOD had little knowledge of LPAs and provided very limited information to service personnel. Following communication with AST’s founder, the MOD did release a defence information notice (DIN). Powers of Attorney are mentioned in welfare booklets. However, even though the MOD provides information to discharge their duty of care, the message does not appear to be getting across effectively resulting in service personnel at all levels remaining increasingly vulnerable. LPAs can be used to support in various ways, not just when temporary or permanent mental incapacity occurs. The Property & Financial Affairs LPA, can also support those who have severe life changing physically injures such as blindness and/or loss of limbs. The LPA can support those on deployment as it will give a legal platform for those appointed to deal with day to day matters, and importantly it can be used to assist those with mental ill health such as Post Traumatic Stress Disorder (PTSD). As by working in partnership with the donor, the attorney can support the individual.

- **12.2 Lack of sustainable accessible and affordable support:** For those who do wish to prepare, the extremes of current service provision result in lack of engagement. The average reading age of an infantry soldier is 9 to 11 years. There will always be those who will prepare themselves who have ability, and there will always be those who will pay a profit making entity for creation of a document (£500.00 is average). However, there are a vast majority who will not engage due to lack of skill set, affordability or education and it is this group that are currently vulnerable, because of the lack of sustainable, accessible and affordable support.

- **12.3 Certificate Providers (CP):** Due to the nature of service, personnel move geographical areas on regular basis, the ability to have a friend based CP to act is therefore reduced without incurring a significant time delay. Engaging the services of a skills based professional CP is highly likely to incur cost (on average £60.00 to £150.00). Commanding Officers currently are not considered acceptable to act as a professional CP unless they can demonstrate that they have a working knowledge of the MCA.

- **12.4 Cost of the registration fee:** The cost of the registration fee (£130.00) per document is a severe block to engagement for many. This
results in some of those who choose to prepare an LPA considering a ‘half way house’ namely preparation without registration. Registration is a matter of personal choice. There is a risk of failure if registration is left until after mental incapacity occurs. This results in the individual requiring COP intervention, increased financial burden and likely input from third parties. The OPG recommend registration straight away.

12.5 **Administrations:** The majority of service personnel believe that their next of kin (NOK) will be able to automatically help them and that a Will can assist before death and is all encompassing. Unfortunately, in both cases this is not the case. Unless NOK are detailed in a registered and valid LPA, they have no legal platform from which to speak and act. NOK appointments keep costs to a minimum, however there are a significant proportion of the AFC who do not have or would not want to have NOK appointed. The lack of affordable service provision for administrations acts as a block. Research shows that many will not engage with a solicitor.

12.6 **Requirements for Scotland, Northern Ireland and Commonwealth:** It is acknowledged that there is limited support for those who come from the above, and whilst this evidence relates to the MCA of England and Wales, those service personnel from the above countries, seek assistance and guidance to prepare for possible lack of capacity with the equivalent document and also an LPA if they hold assets in England and Wales. Northern Ireland operates under the EPA system, and only when capacity is diminishing does the document need registration and fees to be paid. Scotland has different again requiring registration before the document is used.

13. The Armed Forces and Reserve Forces (Compensation Scheme) Order 2011 (AFCS) sets out how service personnel are to be supported if injured. If mentally incapacitated, the time delay in appointing a deputy via the COP can be considerable. The Compensation Scheme makes provision of an appointee to manage the AFCS award. The Service Personnel and Veterans Agency (SPVA) can appoint that third party to act and administer the award. Clarification as to who regulates the SPVA, how the appointees are supervised, and what redress is available for those who suffer financial abuse would be beneficial to all. If a compensation claim takes into account deputyship fees, or if the settlement does not, those fees charged by a professional deputy are funded from the tax payer and public purse.

14. Making an LPA is a matter of personal choice as is a Will. Service personnel and their families cannot make an informed decision and choice if they are not aware of all the facts and options giving them ability to choose. What AST delivers is an engaging, accessible and affordable way of providing third sector assistance and guidance by coordinating all sectors involved with LPA provision.

15. This requirement for accessible and engaging support to complete an LPA is illustrated by the Armed Forces example. However work by AST shows that need is also in our wider society. It does not just apply to service personnel but to the larger cross section of our community who do not have the skill set or

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ability to prepare themselves or who do not wish, or do not have funds to engage with a professional charging for creation of a document.

16. There is a chain of pain caused by the MCA. If individuals are not prepared correctly for mental incapacity. The financial drain and welfare ramifications will affect not only individuals but also families, third parties, Local Authorities, Charities the NHS and Government Departments.

17. With an ageing population, some of whom have limited assets, consideration needs to be given not only to how they are going to pay for their care costs as they age, but how they are going to pay for their administration costs if needs be. The MCA does not seem to distinguish between those with assets and those without. It is foreseeable that there will be an ever increasing tide swell of need if engagement and correct preventative preparation is not found.

18. Appointment of lay attorneys and deputies, if chosen, help to keep costs to a minimum, thus increasing self-sustainability. Until now the only other option has been to utilise the services of a professional from a fully commercial and profit making entity (solicitor or accountant) which rapidly uses funds. The extremes of service provision equate to all or nothing, and whilst appointment in the main is personal choice, choice has been limited and restricted.

19. A proactive and preventative approach from the third sector to support community groups to prepare, rather than reactive historical methods supporting those in financial difficulty is urgently required. The SAB of AST recognised the need for a preventative strategy. An LPA is a legally binding document, but preparation is not a reserved legal service. You do not need to use a solicitor, it is a preparation for welfare (albeit financial and/or health). Urgent consideration needs to be given by charities and Government as to how they will support increasing requests for financial support to pay for PAAs and Deputyship fees for those who have not prepared correctly. Administrations are not a legal service, but by default they are and traditionally have in the past been provided by the legal sector. The current trends are unsustainable.

20. To be prepared and have the ability to support and safeguard ourselves during vulnerable times, can only come about if we understand the need. When understood through informed education, we all should have options, opportunity and facility available to prepare so that when we are truly vulnerable the support we have planned for is delivered in a safe, secure, affordable and sustainable way.

21. AST are recognised as one of the leading experts as regards LPA provision and have a detailed breath of understanding of all sectors from end users to IT provision, the wider social ramifications and user engagement. AST have enormous experience from research and engagement and have taken time to deliver a strategy and structure that is sound with good working practice that will become self-sustaining and one that is scalable and replicable. Our ethos of operation is preventative actions to “Take Responsibility” to preserve funds and reduce financial burden. Financial self-sustainability and independence is beneficial long term across individual, private, public and third sectors, supporting personal choice.

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22. To date failures from various sectors to engage, to foresee, consider and implement anything other than a reactive strategy has led to the MCA being likely to cause a tidal wave of need in the coming years.

23. We are guided by a statement “the law is for the people, the people are not for the law” and that statement should not just apply to the creation, development and application of the law but also to the provision, delivery, accessibility and affordability of the law.

30 September 2013
TUESDAY 16 JULY 2013

Members present

Baroness Browning (Acting Chairman)
Lord Alderdice
Baroness Andrews
Baroness Barker
Baroness Hollins
Baroness McIntosh of Hudnall
Lord Patel of Bradford
Baroness Shephard of Northwold
Lord Swinfen
Lord Turnberg

Witnesses

George McNamara, Head of Policy and Public Affairs, Alzheimer’s Society, Peter McCabe, Chief Executive, Headway, and Paul Farmer, Chief Executive Officer, Mind

Q90 The Chairman: Good morning. Thank you all very much indeed for coming along to give evidence to our Committee this morning. I am chairing the Committee today—I am Baroness Browning—because our chairman, Lord Hardie, is unfortunately unable to be with us this morning. But a very warm welcome, and I am sorry if you have been kept waiting beyond the time we had hoped to start this session. Could I just remind you that this session is webcast, so it is being broadcast live, and there will be a transcript that will be sent to you for the usual procedure, with any corrections or alterations that you may wish to submit.

Could I begin by asking the first question of all three of you? That is, at the time the Mental Capacity Act was passed it was widely viewed as progressive and was a welcome piece of legislation. In your opinion, has the Act lived up to its expectations, and are there benefits or problems that were not foreseen at the time the legislation was passed?

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
I have just realised, Mr McNamara, I must declare an interest as vice-president of the Alzheimer’s Society. Having got that on the record, perhaps I could ask you to start.

George McNamara: Thank you very much, Chair. Our view is that the Mental Capacity Act has not lived up to its expectations. In theory we think it is absolutely right in terms of producing a framework, but in practice we are not convinced this has worked most effectively to benefit people with dementia and particularly their carers as well. I think in terms of going forward and looking at some of the key areas, quite clearly for us and what we are picking up in terms of our supporters has been a lack of awareness and understanding of the Act, and that is in two main areas.

The first, in terms of the health and social care staff profession, but also secondly, and increasingly in terms of the contact we are having, is with carers and family who are affected by loved ones who have dementia as well. So, we think that needs clarification around the purpose of the Act, but also a real raising of awareness of how it can work and the benefits of it in practice can make a real difference.

Peter McCabe: Hello. I think our view is that the Act has generally been well received but, as with all things, you can make it better. The specific suggestions that we would have there would be to simplify the guidance on best-interests decisions; to create brain injury-specific independent mental capacity advocates with a real understanding of brain injury—that is a very specific condition—to ensure that mental capacity assessments are performed by appropriately trained staff, particularly staff with an understanding of brain injury; to simplify the process for appointing deputies; and to require more regular supervision. We have a real concern about how that is going, and we think there is a need for further training and clarification for medical professionals because, although generally we feel it has been well received, there is a significant difference between best practice and what we hear about from service users, which is worst practice.

Paul Farmer: Thank you. I think, like other panellists, we would agree that the Mental Capacity Act was a good piece of legislation. It promoted an enabling and participatory approach, and it created the prospect for a much more level playing field, if you like, in terms of the rights that individuals had in these often very difficult situations. So, the principles that were clear and very straightforward, including this presumption of mental capacity, I think were real positives.

Like others, I think we would also agree though, that there have been real challenges in the implementation. I think there are particular issues around the deprivation of liberty safeguards that I am sure we will get on to later on. I suppose, in particular in the context of people with mental health problems, there is a question of the interface between the Mental Health Act that was passed subsequent—or the latest iteration of it—to the Mental Capacity Act and the Mental Health Act. Particularly from the point of view of both health and social care staff but also patients and their families, I think that has created a kind of gap in terms of the levels of understanding, but also an easy and effective pathway to both information and also to advocacy.

Q91 The Chairman: Thank you. When you are assessing a person, is it the case, then, that the Mental Health Act as now constituted provides—I will not use the word an “easier” route, but is it more straightforward and less time-consuming in terms of, say, an assessment of somebody than to go into the capacity where there may well be just not a “yes or “no” answer but a fluctuating capacity in some areas? What I am
trying to get at is: is it the soft option to go down the mental health route rather than the time-consuming assessment of someone’s capacity?

Paul Farmer: I would hope that the Mental Health Act was never seen as a soft option. I think it would also always be seen as a last resort and there are very appropriate safeguards wrapped around mental health legislation to try to make sure that is the case. I suppose it is conceivable that, in an environment where mental health legislation has been applied by health professionals over a much longer period of time, some professionals will be more used to the administration of it and so there will be a greater degree of usage of it.

Perhaps where there has been an underestimate is the underestimation of the culture change that has been required in terms of thinking about the nature of the interaction between the staff and the individual and their family. So, it is not so much that it is necessarily an either/or, but I think it certainly created a real challenge for staff in terms of changing some of the dynamic. When it comes to mental health legislation, for some health and social care professionals the question for them is about which route is the best and most appropriate route for them to use. That is building in an additional layer.

For individual patients and families, at the moment the access to appropriate information and advocacy is not joined up, so your entitlement to advocacy comes in at different points, and often there is no reason why anybody who has not had any contact with the whole question of mental capacity or mental detention under mental health legislation should know which is the right group for them. So, there is not a straightforward explanation of what each Act means and what individuals’ rights may be under each particular piece of legislation.

Q92 Baroness Andrews: We have heard quite a lot from witnesses about the challenge of the culture of change and the difficulties of implementation. One of my questions is: do you think that there is something we can do about the Act itself and the definitions, for example? I think, Mr McNamara, you talked about clarifying the purpose of the Act. Can you expand on that and give us some ideas about it?

George McNamara: I think that there is already the code of practice that is in place, and it is raising awareness about that document. It is quite a weighty document in itself for the lay person to wade through it and fully understand it. There must be more simple ways of doing that. Secondly, the key thing we would look at is deprivation of liberty safeguards and having a clear definition of what that means. I think they are two of the key things we would like to see.

Baroness Andrews: You used the term “simplification” a couple of times in your evidence. Do you think it is possible to simplify either the code or the definitions in the Act in some way as to make it more easily implementable?

George McNamara: I think there are two sides to that coin. One is making sure it can be more easily read, and that there are explanations as well. But I think the other side of that is having access to advice—specialist advice—so, for example, where questions may arise as a result of reading the code of practice, that there is easy and accessible access to answering those questions, where at the moment there does not seem to be that.
Baroness Andrews: A further refinement, if I could ask your two colleagues, of the code of practice would be welcome: do you think it could be done effectively?

Peter McCabe: I think to simplify guidance would be helpful to enable people to know specifically where they stand. But then there is this whole issue of training. You can clarify things and make it as simple and easy to follow as possible, but if people are not given the time to understand the concept of what you are driving towards, then they will not do it. We find carers of survivors of a brain injury often find that they end up knowing more about the Mental Capacity Act than some of the staff that they are dealing with, and they are having to explain that to them. That surely is not right, and that has to be addressed, I think.

Baroness Andrews: Very interesting. May I follow up with just one question arising out of this morning’s evidence which took us slightly by surprise? We were told that local authorities are also producing their own guidance and it is not statutory guidance in the sense that some guidance is, clearly. But this is supposed to be helpful advice for the practitioners who are implementing the Act on the ground. Have you come across that? We were conscious that we were receiving evidence that there might be a layer of confusion being introduced by local authority guidance, either because it was inconsistent between authorities or inconsistent between professional groups. We would like your comments on that, if you have experience of it.

Paul Farmer: I am not aware of that, although it would not surprise me on two grounds. First of all, local authorities do have some responsibility around the commissioning of advocacy in this area, and so you would expect them to want to try to interpret it. But I think it maybe points to a gap, and where there is a gap then different people will seek to fill that gap. Just to very briefly come back, if I may, to your earlier question about the code, I think perhaps a particular area where clarity would be helpful would be in the definition of deprivation of liberty, and having a clearer definition of deprivation of liberty that relies on criteria that are more easily identifiable so it is easily applicable for frontline staff, I think could really help.

Baroness Andrews: Thank you very much.

Q93 Baroness McIntosh of Hudnall: Can I just follow up that particular point, because I think we have heard now several times from different witnesses that somehow the deprivation of liberty definition is unclear? Given that you have clearly given a lot of thought to it, can you see how there is a way in which the clarity that you seek could be written in, or is it one of those intractable problems that lots of people have bent their brains around and have not yet come up with an answer?

Paul Farmer: There are certainly areas where I think we can help. We were involved in the construction of this as part of members of the Making Decisions Alliance many years ago, so we understand the complexity around this issue and I know you have heard from other witnesses around this. But, I suppose, the advantage with looking at this legislation at six or seven years into its implementation is that you can draw on the experience of people on the frontline to help create that clarity.

What we hear is that it is the frontline staff who find that current definition quite unclear. I think it would be helpful to see an objective test that relates to the arrangements for the person’s care rather than how they present. We have certainly
heard of instances where a person has stopped objecting to arrangements for their care, so the DoLS authorisations have been lifted but the arrangements for their care have not changed. So, the DoLS test needs to be applied quite objectively, I think, on that.

So, there is something about the definition, but then there is also something about the guidance around the application, and I think that is where the code and, indeed, any more consistent guidance that might be produced for or by local authorities will be important, because I think that area is where we have certainly seen that has fallen down.

**The Chairman:** I am going to ask Lord Patel to come in here because he has a question that is related to this, and we will take it now.

**Q94 Lord Patel of Bradford:** It was interesting, Paul, because you described the Mental Capacity Act as an enabling a participatory approach into use. Others would argue that the DoLS—and I think you have begun to argue that—probably has not had that enabling approach. Yet the Department of Health very clearly, in the evidence they gave us, said it was because of the focus that people had honed in on the deprivation of liberty bit and had not focused enough on the safeguards bit, and they felt that it was going in the right direction. You obviously clearly would like to change some things, but do you agree with their assessment?

**Paul Farmer:** I think quite often the word “safeguards” is left to one side, so I think there is some validity around that, and often the nature of safeguarding is not sufficiently emphasised. So, we know that when the safeguards work well they encourage the staff and the service providers to think about the restrictions that are being placed on that individual. So, they are placed on that individual in a minimum way, and I think that is a positive way to encourage staff to think about the application of this.

So, rather than think about this as being one of the times when you deprive someone of their liberty, you think about what are the safeguards that you should be putting in place. So, there has clearly been an emphasis around this. I think sometimes staff think that because they are providing care and acting in the person's best interest, they must not therefore be depriving the person of their liberty.

It comes back to my original point about the quite fundamental culture change that the capacity legislation requires for some staff who do not necessarily think about the patient as an active participant in their families, an active participant in care. Certainly, work that was done for the Mental Health Alliance by Roger Hargreaves found that this kind of reaction was something that they have found among staff. For those safeguards to be effective, the deprivation of liberty aspect needs to be clear.

**Lord Patel of Bradford:** You would not go as far as to say that we should change it and go back to the guardianship in the Mental Health Act?

**Paul Farmer:** I am conscious that you are currently looking at the Mental Capacity Act, and I am tempted to have a longer discussion about the interface between the Mental Health Act and the Mental Capacity Act, because I think it does particularly have a role in the context of people with mental health problems. There were certainly some aspects of guardianship that I think had real strains. There is, however, a wider
population that could potentially benefit from the deprivation of liberty safeguards, so one would have to weigh those two issues are quite carefully.

If you allow me just to make a very brief comment on this, in the longer distant future, we would encourage a quite careful reassessment of the interface between mental capacity and mental health legislation. We would not necessarily encourage you to be doing that now, because both pieces of legislation do need time to properly bed in and be applied. Our position, in a sense, would be unchanged, that there would be a great virtue in looking at a capacity-based mental health legislation, but I suspect that is not a task for this Committee but it may be something you might want to consider as a future recommendation for a further committee.

Q95 The Chairman: Thank you. There was a lot of discussion at the time as to exactly where to plug the Bournewood gap, and it was decided eventually that it would be plugged in the Mental Health Act. I suspect that discussion still goes on. Do you feel the Bournewood gap has been plugged adequately?

Paul Farmer: No, I think the message that is coming clearly from many places is that the gap is not sufficiently working. Conceptually, legislatively it looks like it has been plugged but in terms of practice it does not look as though that has really worked. We already have a number of different Government Departments with an interest in this particular area. The Department of Health and the department for justice have an interest. We also see local government having a role, and I think that is clouding the issue when it comes to effective implementation.

Lord Patel of Bradford: Are there any issues with brain injury and deprivation of liberty safeguards at all?

Peter McCabe: I am not aware of there being major issues in that area.

Lord Patel of Bradford: Just to pick up from what George said about seeking advice on the code of practice, when the Mental Health Act Commission existed, besides all the commissioners that went round to hospitals, we had this staff team who were administrators who used to answer the phone all the time. If any nurse had a problem or issue about the code of practice, they would pick up the phone and talk to the administrative team, who spent all their day looking at issues about the Mental Health Act code of practice, and they would have an answer. If something like that was available, do you think you it would plug the gap in terms of understanding or simplifying this code of practice issue?

George McNamara: I think it would go some way. From our own Alzheimer’s Society helpline in the last year, just on the Mental Capacity Act, we had over 2,500 enquiries just from people concerned with dementia.

The Chairman: Thank you. Before I move on to Baroness Barker, could I just ask you what I asked our previous panellists, all from the charitable sector? That was, if your charities produce resources and literature that are used to advise parents, carers and others, we would be very grateful to receive them, either in electronic form or hard copy, because we are very interested to see what the charities are doing to help, advise and give information to people. Thank you very much. Could I move on now to Baroness Barker, please?

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Alzheimer’s Society, Headway and Mind – Oral evidence (QQ 90 – 105)

Q96 Baroness Barker: Hello. Today, as with witnesses on other days, you have already highlighted for us that there are different professionals having different levels of understanding in practice of the Act. From what we have gleaned so far, people seem to think that frontline social workers probably have a fairly good understanding and awareness of the Act whereas different medical staff, and in particular GPs, tend not to. Also, Paul, I was interested in your comment about settings where people are familiar with the mental health legislation already having a bearing on their conduct and what they do. In view of all of that, do you see a need for training and different sorts of training for different professionals in order to get this Act implemented in the way that it was envisaged it should be?

George McNamara: I think training and awareness is absolutely vital. When you look at the number of LPAs that are being issued, if you look at the split between the property and finance and health and welfare, there is quite a distinct difference. I think only 20% have been for health and welfare between 2007 and 2012. It has been quite interesting, because the work we have been doing with particularly the financial sector, they have now recognised this is a growing need, particularly for their customers, in terms of providing a service that protects savings but also enables protection against fraud as well as access to financial services.

The work we are doing is being driven by the financial services looking at dementia-friendly financial products, of which this LPA is one aspect. A survey we did a couple of years ago found that three-quarters of respondents thought that bank staff needed a better understanding of what a LPA is, so it is not just within health and social care. It goes beyond that. There are examples we can provide in addition to what we have already submitted.

I think in terms of health and welfare, again what we are finding is that carers are being asked, for example, to make decisions and they are unsure themselves what their remit is. So, there is need to have clarity around training in health and social care and particularly when looking, for example, with dementia around fluctuating capacity where it is looking in the best interests, not necessarily solely around what safeguarding should be.

Peter McCabe: I think you mentioned frontline social workers having a good understanding of the Mental Capacity Act or being seen to. Our difficulty is that they do not seem to have a very good understanding of brain injury. We do not fit into the boxes, the silos within an adult social care department, so very often our service users are neglected and there are so few social workers. There is an excellent brain injury social worker group, but they are tiny. We constantly try to encourage local authorities to undertake training of their staff so that they do understand those issues. I think another issue with social workers is that a lot of our clients say they very rarely see them and have little support for adult social care from social workers, so there are big issues there.

But coming back to the issue of training, do they need training? Yes. Do other professionals need training in the Mental Capacity Act? Yes. It needs to be right across all the groups that are involved in meeting the needs of our clients.

Q97 The Chairman: When you have somebody who is severely brain-injured, say, for example, as a result of an accident, but they make progress, how would you feel they...
are dealt with when they may not have capacity or they have very fluctuating capacity but need every opportunity to make progress where they may regain almost all of their capacity? How is the Act working in respect of people who have the potential to regain capacity?

**Peter McCabe:** I think the answer to your questions is in many cases it would depend on what part of the country they were living in as to the kind of response they got.

**The Chairman:** Are you able to elaborate at all where it is a good place to live or a bad place to live?

**Peter McCabe:** I think there are more bad places to live than good places. There are some excellent examples of community-based services for survivors of a brain injury. They are increasingly under threat from all the changes that are taking place and it is seen very much as a small special interest rather than something that should be provided mainstream. But I do have some experience specifically of a case where a gentleman who was deemed to lack capacity at one point subsequently was assessed as having sufficient capacity to take on the role of looking after his own finances. He had a very substantial settlement from a personal-injury claim that followed the injury that he sustained. He has done that very successfully. There were obstacles along the way but the understanding I have is he did not have a great deal of support during that process from adult social care but an enormous amount of help and support from his wife, in particular. The burden fell very much on her.

**The Chairman:** Thank you very much.

**Q98 Baroness Barker:** Are your organisations involved in delivering training on the Mental Capacity Act?

**Paul Farmer:** Yes, we do some of that and our sense would be that there are three layers to consider this. There is what I would describe as the frontline staff culture training session, which is to really imbue that idea of supported decision-making and safeguarding. It is not necessarily about the technical aspects of the legislation, but it is about the spirit of the legislation. It is what the principles of the legislation were originally designed to create, an environment where people are able to make as many decisions as they can for themselves but there are occasions where that is not possible. That kind of culture training is really needed.

Then, secondly, there is a layer of training for those people who are involved in the decision-making processes—who are they, where to use the legislation, particularly the point you have made, Baroness Browning, around the nature of fluctuating capacity and how you manage that in individuals, which will certainly occur in people with mental health problems, conditions such as MS and so on.

Thirdly, there is a layer of training for people who are involved in both mental health law and mental capacity law to support them in being able to use each particular piece of legislation in the most appropriate way and to recognise that there are both benefits and dis-benefits to each particular form of legislation.

We would see this as a layered approach. Of course, wherever possible, it is obviously best if you can encourage that training to be taking place in a multi-disciplinary context.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
so that the social workers who maybe get this a little bit more are able to share their experiences with clinicians. Quite often that multi-disciplinary approach can help to break down some of those barriers.

Q99 Lord Swinfen: Are families, carers and individuals who may lack capacity aware of and able to access their rights under the Act, including through the role of independent mental capacity advocates and the Court of Protection?

Paul Farmer: Not sufficiently, in our view. I suppose my initial point is that most people who are engaging with this situation in the context of their family or loved one probably do not even know the Mental Capacity Act exists. There is an information gap in terms of their engagement with the services. We have seen some very good practice. A number of local Minds run advocacy services, but they are often extremely tightly funded and susceptible to funding cuts going forward, and because of the multi-site nature of those areas where capacity legislation could conceivably apply it is quite difficult for advocates to get themselves around so that they are able to be present at the right point.

I suspect that may be one of the reasons why you are finding that local authorities are producing guidance almost to try to fill that gap. We certainly would like to see a more joined-up approach to commissioning of advocacy.

Peter McCabe: I would agree with Paul. There is not sufficient access.

George McNamara: Yes. The increasing numbers of enquiries to our helpline—just on the Court of Protection aspect, there are two things that we are picking up. One is that it is quite expensive; £400 then plus any additional legal fees as well. Also, it is quite slow in terms of the decisions to do that. One of the examples that we have had in terms of accessing information and guidance was when somebody responded to us by saying that they received the deputyship certificate last week but do not understand what they are meant to do next. Is the COP going to send any guidance regarding how to use the certificate to sort out Dad’s finances? That is just one example really where people are looking for further questions beyond what has been provided.

Lord Swinfen: What training do you do of your staff and of those people who suffer from mental incapacity?

George McNamara: From the Alzheimer’s Society’s perspective, we support providers on dementia awareness training for specialists but also for wider sectors—for example, as I have talked about, the banking sector. So we provide it from the dementia perspective to make sure that it is part of a holistic training package, and is not just seen as a separate addition because it needs to be integral, given the high number of people with dementia who are using the health and social care system and also other services as well.

Baroness Andrews: Do any of you know whether the networks have taken on board the MCA and whether any groups have been involved in these networks, because they were supposed to do some of this sort of work? We have not had a reference to them yet. Maybe you could let us know in some other way.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
The Chairman: Perhaps you could write to us on that? Thank you very much. Baroness McIntosh has the next question.

Q100 Baroness McIntosh of Hudnall: Yes. We have already talked a bit about IMCAs, and obviously they are a very important part of the ability of people to get the benefit of the MCA. Do you think they have succeeded in doing what they were supposed to do? I notice, Mr McCabe, you made reference earlier on to the lack of IMCAs with a specific expertise in relation to brain injury. Two particular questions: one, do you think in absolute terms there are enough advocates out there to cover the range of need that we know there is, and is there, as we suspect, quite a significant regional variation in where they are and how they are deployed? Secondly, are there enough opportunities for them to acquire the kind of specific skills that you have already referred to? That would extend to, for example, skill in dealing with people who are severely learning-disabled or have dementia, who will all present with different needs and require different kinds of advocacy. Is it possible to train advocates to cover all of that?

The Chairman: Mr McCabe, do you want to start?

Peter McCabe: I do not think there are enough. That is what I am hearing from our regional set-up around the country. Could they acquire the specific skills? Yes. In our case I think that there are some issues that would overlap across a number of conditions and there would be some that are specific. We offer training to social care staff, to health professionals, a wide variety of different groups specifically in brain injury. It is not something that takes for ever but does give them the basics to enable them to deal with our service users and meet the needs of our families.

George McNamara: I think they are very much valued in terms of the roles, particularly given it is independence that is important, something that we feel needs to be better promoted. There is no promotion around the roles and accessing these advocates either. I think that is vitally important. It is really left up to the advocates themselves to promote their own service, and if you have a heavy caseload already, that would be an add-on part.

In terms of your first question around “Are there enough?”, and linking to your second question about skills, the figures we had from the Department of Health found that 38% of referrals to advocates were for people with dementia, so that is quite a big proportion of people. Looking at the current customer base, it would not be that difficult to make sure that there is a specific dementia element that could cover a significant proportion of need.

Baroness McIntosh of Hudnall: Just as a matter of interest, who are they? Are they lawyers generally? Are they social workers? Are they people who just have a general interest in this area? Or are they a mixture of all of those things?

Paul Farmer: It will depend on the provider, first of all. There are a range of different providers in this. It is a market, essentially, because it is commissioned. There will be private and voluntary and indeed public sector providers, mainly private and voluntary sector providers. Their backgrounds will be very mixed. They might be people with some relatively low-level legal experience and qualifications. They might be people who have come from a social-care background. They may well be people who do not...
necessarily have a formal qualification at all. In our experience the best advocates are those people who do have some reasonably good grasp of the law. I think that is really important. That quite often means paralegal-type background potentially. But we are also talking about those people who have had some proper understanding and experience of the health and social care system so, as well as being advocates, they are also navigators. They are navigating people through the system.

Baroness McIntosh of Hudnall: I am sorry, I have gone slightly off-piste here, but it strikes me as interesting that it sounds as though there are relatively few standard criteria that would be applied in deciding whether somebody would or not make an effective advocate, for this type of advocacy.

Paul Farmer: Perhaps to bring you back on-piste, it is a very fragmented area and there is an absence of a national lead body for all advocates promoting standards and developing good practice. That may well help certainly to address this question about effective quality. We know that there are some fabulous advocates out there who do a really terrific job for their clients, but we also know that there are potentially less fabulous advocates. There is no central body to really look at this in any sufficient depth. It is partly a product of the way in which the commission of the services were created in the first place. As you know, they are mainly commissioned by local authorities, mainly with relatively small pockets of resource and the resource, broadly speaking, pays for the running of the service. Comparatively, there is very little by way of professional development, for example, for those advocates.

The Chairman: Providers will be in front of us next week so you have given us some useful ammunition in preparing our questions. Thank you. I am going to ask Baroness Hollins to take to the slopes now.

Q101 Baroness Hollins: We have heard very contrasting views about how easy or difficult it is to assess capacity in practice; also, that in some situations practitioners move straight to best-interests meetings without assessing capacity first. What I would like know is—perhaps taking into account whether it is somebody with dementia or head injury or serious mental illness—about your own experience in practice and whether there are any particular issues with respect to particular impairments and particular settings and particular professional groups. Who would like to start?

George McNamara: Just a couple of points; one of the areas that is often overlooked is involving families in being part of the code of practice, but families are often omitted from looking at this in terms of the best interest. Also linked to that is looking at the past decisions and future wishes as well. That is often something that is overlooked. When it comes to capacity, obviously for people with dementia it is quite important to recognise the fluctuating capacity that, for example, somebody may not be able to deal with their finances but can quite easily do many day-to-day tasks. They are a couple of the areas that really need to be addressed in terms of best interest in capacity from the Alzheimer’s Society perspective.

Baroness Hollins: You are describing quite a skilled assessment. There are a lot of skills from a practitioner to do it properly?

George McNamara: Yes, and we should not be looking at any shortcuts here. This is absolutely vital to make sure that a thorough assessment is taking place. Particularly for
people with Alzheimer’s disease, the progressive nature of it means that their needs and their capacity will change as they go down the dementia journey as well.

**Peter McCabe:** With our service users there are all sorts of complexities; and one is that capacity can change over a period of time, and that presents some challenges. Then issues like lack of awareness and insight, impulsivity and inflexibility can create problems for people who are trying to make those assessments. One of the issues with survivors of a brain injury can be that they can be very good in terms of their presentation and giving you the answer that they think you want to hear, whereas the carers and their families would have a very different story. That is a difficulty we have to acknowledge and recognise.

**Paul Farmer:** Just a brief point: I refer you to the comments made by the CQC around assessments of capacity in psychiatric units and also people subject to community treatment orders. I think that is an issue that they have certainly identified as an area for further concern.

**Baroness Hollins:** In in-patient and community settings do you see a difference in practice?

**Paul Farmer:** Not hugely. The question is, I suppose, for people who are in in-patient settings but who are not detained under the Mental Health Act, which is an increasingly small number of people. The skill set is certainly there to be able to carry out the assessments. The environment can make that quite challenging in terms of enabling people to make their own decisions in those settings. In a community setting there are other issues at play that may be more around the enabling of people to take their own decision, but again, recognising this question of fluctuating capacity and there, of course, there are similarities with my colleagues.

**Q102 Lord Swinfen:** Do assessments of capacity and/or best interests achieve the right balance between protection and empowerment? Are sufficient efforts made to support decision-making before moving to an assessment of capacity?

**The Chairman:** Who would like to start on this? Mr McNamara.

**George McNamara:** The answer to that is not always the case. This is very similar to the points I have made in answer to the first part of this question. One of the key things we look at, for example, when looking at staff training and awareness that we have talked about is around recognising different methods of communication for people with dementia. One of the examples we have picked up on was staff in a care home had just given residents a cup of tea with no other options as part of their day. When asked why this was the case, the staff said that the residents would not be able to answer anyway and that is why they just got a cup of tea. It was suggested to the staff that they should show residents tea and coffee and ask them to point out their choice, so little changes and a little bit of understanding about how different ways of communicating can go quite a long way to improving the quality of life and also engagement with people.

**Peter McCabe:** I think from our perspective it is difficult to strike the balance between protecting people and giving them autonomy. We heard from somebody that was involved with somebody again who received a substantial claim for personal-injury damages, and with that comes all kinds of dangers. There is the sense in which an
individual might be capable of making a decision to purchase an item at a particular point without necessarily appreciating that if it is in a sequence of decisions it could have consequences down the line in terms of managing their resources. They are capable of making the choice between this wide-screen TV or that one, but do they fully appreciate that if they continue to purchase these items there might come a point where it has an impact on their ability to do the things they want going forward? That is a real issue, I think.

**Lord Swinfen:** Are you happy to allow them to make their mistakes?

**Peter McCabe:** I think there has to be that provision, but there also is a responsibility for somebody who is looking after their finances, where they do not have the capacity, to listen to their views but make sure that they do not put themselves in the position where they are without resources or, worse still, can be exploited by sharks that swim around such folk.

**The Chairman:** Thank you. Mr Farmer, did you want to add anything to that?

**Paul Farmer:** Briefly, just to add this, certainly our legal advice staff hear from relatives and carers of people who are not being involved in decisions that they could make, when they go for meals, whether they can smoke or go outside. Just as an aside to the question of financial capacity and capability, there is some interesting work going on with financial institutions to look to see how they could use their anti-fraud systems to detect particular patterns of spending. This could particularly, for example, affect somebody with bipolar disorder, who could go and spend quite considerably when they are in a very high state. There is certainly a growing level of interest amongst financial institutions to look at this. That is quite a good example of where the environment can be created to enable people to make their own decisions but also safeguards can be put in place where their mistakes may become quite damaging in terms of the longer term impact of that. The culture change that is required to get that balance right, which is difficult, can be achieved by some imagination and some creativity.

**Q103 Baroness Barker:** How would you clarify and simplify the code of practice in order to enable assessment and best interest, which are the bedrock of the Act, to be better understood by practitioners and carers?

**Paul Farmer:** I do not think I have a response to that, I am afraid.

**The Chairman:** We seem to have a pregnant pause here.

**Baroness Barker:** In which case, you have already highlighted in your evidence, as have a lot of people, that these things need to be simplified in order for the basic part of the Act to work. If you could go back and think about that and then, all of you come back to us in writing about it that would be good.

**The Chairman:** Could I just follow on to that? The assessments of capacity or best interests: do you think they are happening as stated in the Act? Is that happening?

**Paul Farmer:** Again, you will have identified that there is a patchy picture out there. There is some very good practice happening without doubt but we certainly do hear evidence of the phrase “cursory assessment”. It feels quite light-touch. It does not feel...
very in-depth, because, to do it well, as others have mentioned, it is quite a skill. Sometimes it is not done to the best possible effect, and it can be quite time consuming. We are seeing examples of it being done well but recognising that the time is required. Then we have these cursory assessments that are not really terribly satisfactory for anyone.

The Chairman: We heard from the previous panel of charities that there is perhaps all too frequently an attempt to decide best interest before any attempt to carry out an assessment, whereas, in fact, the best practice should be to carry out the assessment of capacity and then to deal with the best interest. A nod of the head will do; would you concur that that is what is happening in your sectors? Yes, everybody is nodding. Thank you very much indeed.

Peter McCabe: We find it very patchy, but here is a direct quote from somebody who experienced it for her husband: “It was actually done very well. It was not invasive and it is more commonsense questions. Everything was discussed properly to make my hubby understand it properly”. We do hear comments from the other extreme, but I think it is right to give a balanced view to the Committee and give you that direct quote.

The Chairman: Thank you very much indeed. Could I turn to Lord Turnberg now, please?

Q104 Lord Turnberg: Can I bring you back to the carers and the family, who often feel that they are kept out of the loop? Do you think that practitioners keep them out because of a fear that they might be betraying confidences, the fear of getting past some confidentiality with the patient? Do you think they are inhibited in that?

George McNamara: The answer to that is yes, but we do not see that confidentiality should be seen as an excuse for not including family to ensure that the best-interests decisions are made. That is absolutely crucial. It should not be seen as something to hide behind at all. Again, it just links to another aspect, which is recurring throughout this session this morning, around “Is it because of the lack of awareness and training that it is a barrier—that people are hiding behind confidentiality unnecessarily?”

Paul Farmer: The Carers Trust produced a really excellent piece of work called the Triangle of Care, which sets out that kind of relationship between the clinician, the family member and the individual patient or service user. It really resolves well this question around confidentiality. In our experience confidentiality is sometimes used as an excuse for not involving family members, yet we would certainly argue that good-quality clinical practice and good-quality care needs to involve the family because of their understanding of that individual, particularly that individual’s home life and the circumstances of their home life.

Obviously as an organisation that has always stood up for the rights of service users, including sometimes their rights not to involve their families because their families are the problem, nonetheless, most people, including most service users, will acknowledge that that additional insight and information is helpful in getting the solution right. It concerns us, for instance, as we heard last week, that the Caldicott recommendations around access to information seem to be putting up yet another potential barrier for this. There are surely enough examples now to show that sharing of information among
relevant and interested parties in an appropriate, sensible and professional way is the way to achieve not just good-quality care but also safe care.

**Lord Turnberg:** We are all agreed that it should happen.

**Peter McCabe:** Confidentiality can be an issue or it can be an excuse. We also hear that the established practice, the culture of an organisation and the structures that they have, which are rigid, can often be more of a difficulty and cause more problems for families than the confidentiality issue.

**Lord Turnberg:** Clearly there is an issue here. What is the solution? Do we need to redraft the codes of practice or the regulations, or do we need to offer better training and who should do it?

**Paul Farmer:** I think training is probably the answer. Who should do it? Those people who are qualified and able to deliver effective and inspirational training. There is always a real risk about overburdening trainers. There is a leadership issue here as well, for care providers, for trust chief executives, for medical directors. Indeed, for patient organisations and voluntary organisations as well, there is an issue around really trying to create a culture where this issue is approached in an effective way.

**Lord Turnberg:** Could you let us have the Triangle of Care?

**Paul Farmer:** Yes, sure.

**The Chairman:** Thank you. The final question for you gentleman is from Lord Alderdice, thank you.

**Q105 Lord Alderdice:** Thank you very much, Lord Chairman. All of your organisations, of course, are distinguished advocacy organisations but you are also service providers. Indeed, in my part of the UK, either you or sister organisations are sometimes much the largest direct providers of care—everything from support groups through day-care services to care homes. I wonder if you have any particular observations you would like to make about the Act from a service provider perspective that is a little different, perhaps. Any observations?

**George McNamara:** Just generally, as we have talked about the importance of raising awareness and accessing any advice or answering any questions on the implications or the practicalities of the Act—we are a few years into the Act now and its implementation—what is vitally important is that there is a shared responsibility here. It is for the voluntary organisations, particularly those who are working on a day-to-day basis, to really come up with some solutions with others as well—with statutory bodies as well—because that could be quite a powerful route in terms of raising awareness. But also we must make sure, for example, when statutory contracts are being redrawn or redesigned, that this part of the service—this part of the acknowledgment and experience—is absolutely vitally embedded within the delivery of the service and not seen as an add-on or something that is a specialist area because it has to be integral now to delivery of services right the way across the piece.

**Peter McCabe:** From our perspective, there is a strong commitment to the principles of the Act and therefore it has not been a particular issue because staff recognise the
value of what it is that we are trying to do and are keen to deliver. That is part of the culture of our organisation. Would that it were the culture of other organisations, I would say.

**Paul Farmer**: We have asked our network to try to answer that question in a bit more detail, so we will send that on to you. I suppose our primary observation initially was that the challenges that they face in terms of providing frontline staff with the right kind of training and support is in direct proportion to the nature of the contract that they are given. Not all commissioners for mental health services will necessarily recognise the need for the kind of quality training that is needed, so it is an area to be aware of in terms of the importance of protecting training budgets inside commissioned services. Especially at the moment, quite a lot of services are being sliced—let us put it like that. The training budget is often one that can be sliced all too easily—or indeed the potential to free up frontline staff to actually go and receive the proper quality training that they receive and still run the service. It is a relatively minor detail in the nature of commissioning of services, but, to really embed mental capacity in voluntary organisations and all providers of services, it feels as though that training issue is going to be really important.

**The Chairman**: Thank you very much. Could I thank all three of you very much indeed for giving up your time to come and answer our questions? I just repeat the invitation that the inquiry is ongoing, as you know, so please do feel free to make any further written submissions to us that you would like to. Thank you very much indeed.
Alzheimer’s Society – Written evidence

Thank you for the opportunity to submit evidence to this inquiry. The Mental Capacity Act is potentially the most important piece of legislation affecting people with dementia, as at some point almost all people with dementia will be subject to provisions under the Act.

Summary of evidence

- The Mental Capacity Act (MCA) should be the most important piece of legislation affecting people living with dementia; however, it has not lived up to expectations.
- It was designed to ensure that decisions about an individual are person-centred, but this has not been the case.
- There still remains a lack of awareness of the MCA among professionals, as well as individuals and family members. Care home staff particularly lack confidence and often the MCA is not used for every day choices that maintain an individual’s identity, such as what to wear.
- Staff training in the MCA must be made compulsory. It is especially important to raise awareness of best interest decisions to ensure family members are involved in these decisions.
- There is a severe lack of understanding of Deprivation of Liberty Safeguards (DoLS) among professionals, particularly in care homes, and for when an application should be made.
- The definition of DoLS must be clarified in the Code of Practice as a matter of urgency and supported by staff training.
- The Care Quality Commission must do more to raise awareness of the MCA and DoLS. Implementation of the MCA must be sufficiently assessed during the inspection process.
- Carers and family members acting as attorneys or deputies under the MCA find it confusing. They feel uncertain how to judge a person’s capacity on a day-to-day basis. Adequate support for family members or carers is a priority.
- There is a lack of awareness of the MCA among other sectors, for example banking where carers and family members often report difficulties with banking staff recognising Lasting Powers of Attorney.
- Independent Mental Capacity Advocates (IMCAs) are very helpful for people with dementia, yet IMCAs are seriously underfunded and services are patchy across the country. We recommended adequate funding for IMCAs.
- Often people with dementia will receive a diagnosis too late and already lack the capacity to set up a Lasting Power of Attorney, but the Court of Protection is not a feasible option.
- The Court of Protection is a very expensive and slow process. Many carers and family members cannot afford the process, so will pay for bills out of their own pocket. Some family members or carers start the process, but give up as it is too complicated.

1. Alzheimer’s Society

1.1 Alzheimer’s Society is the UK’s leading support services and research charity for people with dementia and those who care for them. It works across England, Wales and Northern Ireland. The Society provides information and support for people with all forms of dementia and those who care for them through its publications, dementia helplines and local services. It runs quality care services, funds research, advises

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
professionals and campaigns for improved health and social care and greater public awareness and understanding of dementia.

2. Background
2.1 The term dementia describes a set of symptoms that include loss of memory, mood changes and problems with communicating and reasoning. These symptoms occur when the brain is damaged by certain diseases, including Alzheimer’s disease. Changes in ability include a reduction in the person’s capacity to make decisions about major life events and circumstances as well as day to day decisions. People with dementia lose capacity over time and the rate at which a person’s condition deteriorates varies from individual to individual. For example, a particular person may not be able to make complicated decisions about their financial affairs, but may still be able to make day to day decisions, such as what to wear, for quite some time. A person with dementia’s capacity to make decisions also fluctuates over time, for example they may be able to make particular decisions in the morning, but may not be able to in the afternoon.

2.2 Therefore, the Mental Capacity Act provides the legal framework which protects and supports people with dementia on issues which surround their mental capacity. It is a very important piece of legislation affecting people with dementia as at some point almost all people with dementia will be subject to the provisions under the Act.

2.3 Alzheimer’s Society receives many requests for information about the Mental Capacity Act and the measures introduced within it. Between April 2012 and March 2013, Alzheimer’s Society Helpline received:

- 417 queries about Court of Protection
- 1356 queries about Lasting Powers of Attorney
- 471 queries about the Mental Capacity Act

2.4 There is evidence that there is little awareness of the Act and that it is often misapplied or not used when it should be.

3. Overview and context

3.1 To what extent has the Mental Capacity Act 2005 (MCA) achieved its aims?

3.2 The MCA should be the most important piece of legislation affecting people with dementia, however, it does not always work in practice and has failed to live up to expectations. In particular, the Act was designed to ensure that decisions about an individual are person-centred, but this has not been the case. Too often, decisions are being made, which are not in the best interests of an individual. Alzheimer’s Society hears stories, through its helpline call service, of individuals being deemed to lack capacity to make a decision, rather than being supported to make their own decisions as intended by the legislation.

3.3 Court cases have shown this to be the case. For example, a woman with vascular dementia wanted to die at home, but care professionals considered this to be too dangerous as she kept falling and they decided she lacked capacity to make the decision. The case went to court and the woman presented her own evidence showing she did have capacity to make such a decision. The judge ruled in favour of the woman.

3.4 Which areas of the Act, if any, require amendment; and how?
3.5 Above all, Alzheimer’s Society believes that it is important to raise awareness of the Code of Practice among professionals and individuals or family members, especially around best interest decisions.

3.6 Furthermore, the Code of Practice for Deprivation of Liberties (DoLS) requires amendment in order to clarify the definition of DoLS. Further explanation of why this is needed is in the section on DoLS below.

3.7 There is also a need to clarify that the personal welfare power of attorney is the same as the health and welfare power of attorney. The Act refers to personal welfare, yet all the documentation and application forms name it the health and welfare power of attorney. This causes confusion among many people and Alzheimer’s Society receives a number of enquiries to this effect. Alzheimer’s Society recommends rewording the Act to health and welfare power of attorney to prevent further confusion.

3.8 At the core of the MCA are its principles and definitions of capacity and best interests. Are these appropriate?

3.9 The broad feeling among professionals is that the definition, test, principles and idea of best interest decision making is accepted and liked. As stated previously, the spirit of the Act is empowering for people with dementia, ensuring that they are able to make as many of the decisions they can still make about their own lives for as long as possible. Nevertheless, the principles and definitions must be followed through into practice. Staff must receive training in order to understand how to implement the principles in practice.

4. Implementation

4.1 To what extent have the five principles of the MCA been implemented in frontline practice? What evidence is available to assess this? Is there a satisfactory balance between enablement and protection?

4.2 Evidence from the Mental Health Foundation (Williams et al, 2012) suggests that the Act is being used in bigger decisions, for example moving into a care home, but less so in smaller decisions. They found care home staff particularly are not confident in using the Act to support decision making with people with dementia.

4.3 How effective was the Government’s implementation plan? What measures were taken to ensure that professionals and families of those who lack capacity know about and act in accordance with the provisions of the MCA? Has it led to sustainable change?

4.4 There remains a lack of awareness among professionals, individuals and families of those who lack capacity of the Mental Capacity Act. Carers and family members acting under the MCA as attorneys or deputies find the MCA confusing, and there is little support for them to be able to use it effectively.

In between April 2012 and March 2013, Alzheimer’s Society Helpline received:

- 417 queries about Court of Protection
- 1356 queries about Lasting Powers of Attorney (approx 5-6 per day helpline was open)
- 471 queries about the MCA

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
4.5 To support people with the processes, Alzheimer’s Society is producing new factsheets about LPAs and the Court of Protection. This information should really be provided by government.

4.6 Is the Act widely known and understood by professionals required to implement it? How does this differ across different sectors, such as health, social care, banking and others?

4.7 Alzheimer’s Scotland (2012) found that the financial sector regularly fails to recognise LPAs. This can often lead to delays and a carer having to pay for bills from their own funds until the matter is sorted out.

4.8 Alzheimer’s Society recommends extensive support and training for everyone using the MCA. This includes resources tailored to meet the differing needs of people using the act in different circumstances, and training for health and social care staff which presents examples of situations which may be familiar to them, where the MCA applies.

4.9 Is the Act widely known and understood by those who are directly affected by it and by their non-professional carers? To what extent does the Act provide protection and reassurance for informal carers? Has the right balance between struck between protection of the carer and protection of the individual lacking capacity?

4.10 Alzheimer’s Scotland (2012) also did research among lay proxies across England, Wales and Scotland. They found carers and lay proxies too were uncertain of the principles of the act and, on a day-to-day basis, they did not always know how to judge whether the person had capacity when faced by them insisting on doing something risky. This was a cause of considerable anxiety and conflict. Alzheimer’s Scotland recommends training for lay proxies. Alzheimer’s Society’s Talking Point is full of people with questions about LPA as they have nowhere else to turn.

4.11 Is there any evidence that the provisions of the MCA affect some groups disproportionately? If so, what data exists to compare representation across different socio-economic groups, Black and Minority Ethnic groups, and gender?

4.12 Research for the All-Party Parliamentary Group on Dementia (APPG on Dementia inquiry, 2013) found a minimal level of awareness of dementia among people from BAME communities. The stigma surrounding dementia in these communities makes it more difficult for people to get the support that they need. Furthermore, there is a lack of support which meets the needs of people from BAME communities. Therefore, this group of people is less likely to have an awareness of the Mental Capacity Act.

5. Decision making

5.1 Are those directly affected by the Act being enabled and supported to make decisions for themselves to a greater or lesser extent than they would have been in the past? Does the means by which the decision is made – ‘general authority’, Lasting Power of Attorney, deputyship, Court of Protection – affect the quality of decision making?

5.2 Under principle 2 of the Mental Capacity Act, it would be expected that people with dementia would be enabled and supported to make decisions. Yet there are still many
issues around person-centred care and training for staff in specific needs and conditions is urgently needed.

5.3 As many people with dementia are not diagnosed or are diagnosed late, fewer people with dementia have powers of attorney in place than could benefit from them. In addition, Alzheimer’s Society frequently hears that people in England and Wales struggle with completing the LPA forms, with finding a certificate provider, and many see the cost of registration as a barrier. Alzheimer’s Society is working with the Office of the Public Guardian to address these issues.

5.4 Attorneys can also experience difficulties as the powers of the LPA are not always recognised or understood. Alzheimer’s Society is working with organisations to raise awareness and improve systems associated with LPAs within organisations such as banks and utility companies through the Dementia Friendly Communities Programme.

5.5 What evidence is there that advance decisions to refuse treatment are being made and followed?

5.6 There remains the issue with knowing when someone has made an advanced decision in emergency situations. The development of electronic palliative care registers in England is improving this, but these do not have blanket coverage of all of England, and are yet to be developed in Wales.

5.7 Has the MCA fostered appropriate involvement of carers and families in decision-making?

5.8 Despite involvement of family members and carers being in the Code of Practice, Alzheimer’s Society regularly hears stories through its helpline that this is not happening. Often when families ask to be involved, they feel ignored. Therefore, training is required for staff to ensure that families and carers are involved. Under the current legislation, there is no mechanism for families to complain if they feel the law has been breached.

5.9 Has the role of the Independent Mental Capacity Advocate (IMCA) succeeded in providing a voice for clients and an additional safeguard against abuse and exploitation for those who have no-one to speak on their behalf?

5.10 IMCAs are considered to be very helpful for people with dementia where they are used. In the numerous and growing number of cases where there is no family this is especially true. The independent nature of IMCAs means that they are particularly valued.

5.11 It is suspected that the majority of cases where IMCAs are used it is in cases involving people with dementia. However, there are few IMCAs compared to the number of people with dementia.

5.12 It is also essential to clarify that individuals are entitled to an IMCA even they have family members who could act as an advocate.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
5.13 Has the level of referrals to IMCAs met expectations? What are the reasons for the regional variations in the number of referrals? Are IMCAs adequately resourced and skilled to assist in supported or substituted decision making for people lacking capacity?

5.14 38% of all referrals to IMCAs were for people with dementia in 2011/12 (Department of Health, 2013) – by far the highest number of cases by type of impairment. Nevertheless, there is low awareness of IMCAs and the benefits of using them. Where they are used these tend to be only for major decisions, such as moving into a care home.

5.15 There is a severe lack of funding for IMCAs and in some areas there may only be one IMCA. In addition, local authorities do not often promote IMCAs and this role can fall to the IMCA themselves who will often already have a large caseload. Individuals will not necessarily know that they have the right to an IMCA.

6. Deprivation of Liberty Safeguards

6.1 Are the safeguards in the Deprivation of Liberty Safeguards (DoLS) adequate? Are the processes for authorisation, review and challenge of DoLS sufficiently clear, accessible and timely?

6.2 DoLS in their current form are not adequate and do not work in practice. For DoLS to work, there needs to be awareness among health and care professionals, training and legal clarity.

6.3 People with dementia who live in care homes or are in hospital are at high risk of having restrictions put on their liberty, as the care home or hospital makes decisions about restraint, locks and other measures which may be to protect the safety of the person with dementia at the expense of their freedom.

6.4 In 2011/12 only 11,393 applications were made for DOLS (CQC 2013). This figure seems low when compared to the more than 200,000 people with dementia who are likely to live in care homes in England and Wales and the large number who are likely to go into hospital in the course of a year. The applications figure also includes applications for all people who lack capacity, including those with conditions other than dementia. Furthermore, it was originally predicted that there would be 21,000 applications for DOLS authorisation in the first year (2009-2010) yet there was only 7,160 (CQC 2011), and we still have not reached this prediction. These figures suggest it is likely that there are people with dementia in care homes and hospitals who are being deprived of their liberty, without the protection of DOLS.

6.5 Alzheimer’s Society believes that DOLS need to be reviewed. There is evidence of lack of understanding of DOLS amongst professionals, including when they should be applied for. There is also evidence that there is a lack of legal clarity about what the term ‘deprivation of liberty’ covers, which may be compounded by individual Court judgements, such as in Cheshire West, which establish a different view of what constitutes deprivation of liberty compared to the original Bournewood case that led to the introduction of DOLS.
6.6 Alzheimer’s Society also has concerns as DoLS has moved to Local Authorities from 1st April, with no representation in health. There needs to be monitoring of what impact this has, particularly in hospitals.

7. The Court of Protection and the Office of the Public Guardian

7.1 Are the Court of Protection and the Office of the Public Guardian sufficiently understood and accessible to all? Are they operating effectively and successfully? What concerns, if any, are there regarding the costs associated with registering an LPA, or with making an application to the Court of Protection?

7.2 The Court of Protection is very expensive and slow meaning that only people who can afford it go through the process. However, the process can be so lengthy that often capacity has completely gone by the time a deputy is in place. Family members acting as deputies and controllers can often find their role so burdensome and lacking adequate support that they give up. Many people just pay bills, from their own pockets.

7.3 Application to the Court of Protection is currently £400 plus any additional legal fees from the solicitor. This is of particular concern for people with dementia as often they will receive a diagnosis too late, so they will not have the capacity to sign an LPA. If the family members cannot afford to go down the route of the Court of Protection, the individual with dementia can be left vulnerable and open to abuse.

7.4 There is also a lack of support for deputies. Alzheimer’s Scotland (2012) found that family members or friends acting as deputies in England and Wales found supervision systems unsatisfactory and that they were unable to access support when needed. Alzheimer’s Society believes that there should be clearer information about the Court of Protection and deputyship, and more support for people taking on the role of deputy on behalf of someone with dementia.

7.5 What has been the impact of the introduction of Lasting Powers of Attorney (LPA), especially with regard to decision making on matters of personal care and welfare?

7.6 There is currently low uptake of health and welfare LPAs – these currently only make up approximately 20% of registered ones. A lack of uptake leads to difficulty when decisions then have to be made where the person’s wishes are not known and no-one is nominated. As one family member said in Alzheimer’s Society’s report into end of life care:

7.7 “[End of life care, particularly if treatments were to be refused] was not a subject which was ever discussed as a family so I still don’t know what his wishes would be. We looked for a living will, but there was nothing. The hardest thing is knowing what to do to make the decision on his behalf. We still, the three siblings, cannot all agree. So we cannot really put anything in place. The decisions will have to be made when the time comes.”

7.8 There also seems to be confusion amongst carers and care home staff, and potentially other professionals, about the extent of the powers. Alzheimer’s Society has heard of attorneys being asked to sign Advanced Decisions on behalf of the donor by care homes – something which is out of the scope of the attorney’s power and would make the advance decision invalid.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
7.9 There is also currently little way of checking if someone is an LPA unless they have the paper form with them.

8. Regulation

8.1 Is the role of the Care Quality Commission in inspecting on the MCA standards adequate and appropriate? Is there a case for additional powers? Should other regulatory bodies, such as health and social care professional regulators, be acting in this area?

8.2 The Care Quality Commission (CQC) should do a lot more to raise awareness of the MCA and of DoLS in particular. It may have been the case that the CQC did not carry out sufficient inspections of implementation of the MCA in care settings; however, we are yet to see whether this situation will improve under the new inspection regime. There is, nevertheless, a need to do more in terms of policing local authority responses to DoLS requests, especially in hospital settings.

8.3 The CQC should be solely responsible for regulation of the MCA. It is possible for the CQC to link it in with other elements of inspection and regulation. Nevertheless, there does need to be a way for people to complain or report violations or abuses of the Mental Capacity Act.

9. Other legislation

9.1 How well is the relationship between the mental health system and legislation understood in practice?

9.2 There is a clear lack of understanding of when to use the Mental Health Act and when to use the Mental Capacity Act. For example, the Alzheimer’s Society helpline receives enquiries from people where they are concerned a member of their family has been sectioned under the Mental Health Act when clearly DoLs should have been used. In one instance, a woman with dementia and cancer was in a hospice in the last days of her life, when she unnecessarily moved to hospital to be sectioned. Sadly, she died en route to the hospital in a less dignified manner. In this case, a DoLS application would have been more appropriate.

2 September 2013
4. To what extent have the five principles of the MCA been implemented in frontline practice? What evidence is available to assess this? Is there a satisfactory balance between enablement and protection?

1. Section 1(6) provides that “[b]efore the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person’s rights and freedom of action” (emphasis added). This fifth principle has come to be commonly referred to as the “least restrictive principle. In my view this is regrettable as it does not fully reflect the context of the principle and leads to some professionals focusing on least restriction detached from best interests. This principle, in my view, is better referred to as the minimum restrictive principle. Careful reading of Section 1(6) clearly shows that the emphasis is on the minimum restriction that effectively achieves the goal of best interest. Mr Justice Lewison confirms in Re P,6 a case involving the making of a statutory will that:

section 1(6) is not a statutory direction that one “must achieve” any desired objective by the least restrictive route. [It] only requires that before a decision is made “regard must be had” to that question. It is an important question, to be sure, but it is not determinative. The only imperative is that the decision must be made in P’s best interests.

2. Jones similarly concludes that ‘[a]s only “regard” must be had to this principle, an option which is not the least restrictive option can still be in the person’s best interests’.7 The Code of Practice to the Mental Capacity Act agrees. It refers to the “less restrictive alternative”. It gives a balance view and adds that:

Any decision or action must still be in the best interests of the person who lacks capacity. So sometimes it may be necessary to choose an option that is not the least restrictive alternative if that option is in the person’s best interests. In practice, the process of choosing a less restrictive option and deciding what is in the person’s best interests will be combined. But both principles must be applied each time a decision or action may be taken on behalf of a person who lacks capacity to make the relevant decision.8

Mr Justice Hedley put it succinctly in Re GM; FP v GM and A Health Board (2011) when he said ‘section 1(6)... is a principle of minimum intervention consistent with best interests’.9

6 Re P [2009] EWHC 163 (Ch).
9 Re GM; FP v GM and A Health Board (2011) EWHC 2778 (COP).

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
3. The Code of practice for the Mental Health Act (MHA) adds to the confusion by actually including a least restriction principle. However, this is in the context of already potentially severe but well defined restrictions that may well amount to deprivation of liberty that the MHA allows in contrast to the enabling and protective functions of the MCA.

4. This emphasis on least restriction therefore sometimes lead to the situation whereby some health and social care professionals effectively disregard “best interests” and focus on what action or decision is the least restrictive one instead of considering restrictions to rights and freedom of a person in the context of his or her best interests. It seems to me that a concerted effort to move away from referring to s.1(6) as “least restriction” to referring to it as “minimum restriction (that achieves best interest)” will better serve people who may lack capacity for particular actions or decisions.

5. A good example of this can be seen in the online guide provided by the British Institute of Human Rights (BIHR) designed to aid the public in submitting evidence for your Committee. The BIHR in trying to simplify and condense the MCA presents section 1(6) thus:

Least restrictive option: any decision or action carried out on someone’s behalf must be the least restrictive on a person’s rights or freedoms (this is called proportionality).

However, on expanding on these principles they rightly note that:

[i]f someone loses capacity to make a decision, the MCA says that another person can make that decision for them, but that decision must restrict their freedom as little as possible and be in their best interests. (emphasis in original)  

6. So it seems to me that it is in trying to condense the principle into a headline phrase that we often lose the essence of the principle. The “principle of minimum restriction that achieves best interests” is indeed a mouthful compared to the “principle of least restriction” although it is more accurate, but even for the sake of brevity the “principle of minimum restriction” will be less contentious and will better serve people who need decision to be taken for them. Above all it will impress on all professionals and carers that the intention of Parliament is to combine the fourth and fifth principles and identify that option that least restricts the person’s rights and freedom of action but yet serves the person’s best interests.

29 August 2013

10 British Institute of Human Rights. BIHR’s unofficial guide to the Select Committee on the MCA 2005: call for evidence
http://www.bihr.org.uk/sites/default/files/BIHR%27s%20guide%20to%20MCA%20Committee%20Aug%202013.pdf
Accessed 9 August 2013 at p7

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Andy Armstrong and Susie Meehan (Safeguarding Adults Mental Capacity Act and DoLS service at Stockport Council) – Written evidence

Overview and Context

**Question 1**: Established a process for assessing mental capacity and making best interest decisions. Prior to MCA practice in this area was a confused mixture of custom and practice, individual interpretation of common law and guess work.

**Question 2**: Amendments required - Strengthening the monitoring of Attorneys via the OPG. Update Code of Practice to reflect subsequent case law including case studies. Further guidance and scenarios regarding 16-18 years olds

**Question 3**: In general the act is appropriate; however should there be a distinction between decisional capacity and executive capacity? This is sometimes disputed.

Implementation

**Question 4**: reference CQC report 2011/12 would suggest implementation is at best patchy at worst non-existent. Locally available information would unfortunately support this view. In addition annually collected DOLS information, and local reports of the use of IMC As, point to the same conclusion. Health provision appears to be less engaged than social care,

**Question 5**: Anecdotal evidence suggests poor understanding across all sectors and the general public, regarding the provisions of the MCA. Those required to act as the decision maker under the best interest process appear to have little understanding of the requirements, and still fail to recognise when they are required to act as the decision maker.

**Question 6**: See question 4. On-going concerns re engagement of other organisations eg banking sector, DWP, OPG, police, CQC, independent private providers of care, managing authorities regarding DOLS.

**Question 7**: No not widely known and understood. The Act better ensures that due consideration is given to informal carers. In some cases informal carers feel disempowered by the establishment of “the decision maker” role outside the family dynamic.

**Question 8**: Notwithstanding any of the comments above the concept of “decision specific” and “time specific “ has significantly changed the culture away from a one size fits all notion of incapacity. The introduction of the functional test, and the move away from a medical diagnosis have been crucial in this cultural shift. The consideration given to making decisions on behalf of people who cannot make them for themselves is significantly greater and more transparent.

**Question 9**: We suggest there is anecdotal evidence that white middle class people are more engaged with the COP and LPA provisions.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Decision Making

Questions 10: CQCs reports indicate, the requirement to adhere to the second principle of the MCA to take all practicable steps to support and enable the relevant person to make a decision is not being robustly implemented. We have no evidence to know if LPAs or Deputies are compliant with the processes and principles of the Act.

Question 11: We have no evidence, regarding this.

Question 12: Yes in adult social care commissioning. However there is anecdotal evidence health and social care providers are still asking for third party consent, rather than carer and family involvement in best interest decision making.

Question 13: Contract monitoring of local IMCA provider continues to evidence significant under usage compared to original expectation. When utilised in individual cases IMCAs have been invaluable in providing compliance with the process and being the voice of the often voiceless.

Question 14: see above re referral rate. We are unable to give any meaningful response, with regard to regional variations.

Question 15: Our experience of IMCAs has been positive in relation to skills and experience however the service has little resilience when resources are stretched e.g. holiday cover

Deprivation of Liberty Safeguards

Question 16: No they are not adequate for the following reasons

- they only apply to care homes and hospitals – should they be extended to supported tenancies and other supported accommodation?
- It still relies on the Managing Authority raising it, which in most cases they are still ignorant of the process.
- There is potential conflict of interest when the RPR is a family member. Should the RPR be a professional who understands the process in all cases?

Question 17: Best practice would be for the MHA and BIA to do a joint visit. As most authorisations are urgent this is sometimes difficult not least given the 7 day timescale. Should the urgent be increased to 14 days? This would also assist with identifying and appointing an appropriate RPR and ensure all relevant persons are consulted regarding the Best Interest Assessment.

No refusal assessment rationale needs to be clearer so everyone involved understands the significance – see question 11. What constitutes “reasonable steps” to ascertain whether or not there is an advanced decision to refuse treatment?

The paperwork is repetitious, time consuming and seems to be unnecessarily bureaucratic.
Andy Armstrong and Susie Meehan (Safeguarding Adults Mental Capacity Act and DoLS service at Stockport Council) – Written evidence

Should service commissioners be included in the list of “Interested parties” for the purposes of information distribution? (see form 12)

DoLS code of practice needs to be updated in relation to subsequent case law.

The Court of Protection and the Office of Public Guardian

**Question 18-21:** We have had too little involvement to be able to comment meaningfully. Anecdotal evidence suggests that the OPG is slow to respond and it is unclear how proactive its monitoring of Attorneys is.

**Regulation**

**Questions 22 – 23:** The methodology referred to in the annual reports seems at best unscientific and at worst meaningless although the conclusions reached reflect our local experiences that the MCA/DoLs is poorly understood and implemented. Could professional bodies be asking for evidence from members with regard to MCA/DoLs training as evidence of professional development? Given the references to MCA/DoLs in the Essential Standards of Quality and Safety, is there an argument for themed inspections focussing on this area of implementation?

**Question 24:** – engagement with managing authorities, (health and social care providers), psychiatric services and commissioners suggest that there is still significant confusion between MCA and MHA legislation.

**Questions 25 – 27.** Not able to comment.

These comments are made by Andy Armstrong and Susie Meehan from the Safeguarding Adults Mental Capacity Act and DOLS service at Stockport Council and are our views and not the views of the council.

Questions 16 and 17 DOLS – The comments relating to these questions are summaries of views expressed by ourselves and the BIAs attending a recent BIA forum.

8 August 2013
SUMMARY

Independent Mental Capacity Advocates (IMCAs) working for Articulate Advocacy CIC, the social enterprise providing the Independent Mental Capacity Act advocacy for Leeds City Council met to discuss the questions posed by the House of Lords Select Committee.

The individuals dealing directly with people with capacity “concerns” cumulatively have more than 30 years’ experience of work under the Act. The evidence submitted in this document reflects their perspective and understanding in the busiest service in England and Wales.

The IMCAs’ daily work includes dealings with public sector care and health services, private care and housing providers, social enterprises and other non-profit organisations. They reported concerns with the institutional culture, responsiveness and training of the NHS, especially in comparison to smaller organisations such as Leeds City Council’s adult social care service.

They have also identified inherent contradictions in the legal approach to the release of funds for people lacking capacity and shortcomings in the administration of powers of attorney.

The advocates have answered the questions directly and from professional experience. The evidence is personal but direct and addresses the frontline effects of the legislation.

INTRODUCTION

1. Articulate Advocacy is a community interest company (CIC) that is wholly owned by Leeds Advocacy, a registered charity and company limited by guarantee. The two companies have been managing the Leeds Independent Mental Capacity Advocacy service (LIMCAs) since 1st April 2007.

2. LIMCAs’ annual report for 2012-13 revealed that the service was – according to data by the Department of Health – the busiest of 60 by local authority area in England and Wales for that year, dealing with 400 IMCA referrals during 2011-12 within the wider Leeds metropolitan district. Demand for the service increased by 18 per cent during that year. In Leeds, Deprivation of Liberty Safeguard (DoLS) referrals during 2011-12 were just 2.4 per 100,000 population, compared with an average of about 20 per 100,000 documented elsewhere by the Care Quality Commission (in the report Monitoring the Use of the Mental Capacity Act Deprivation of Liberty Safeguards 2011/12). The LIMCAs experience is that comparative conversion rates – and the use of alternatives – indicate benefits from the training and awareness work carried out and the maturity of approach that has been accrued in Leeds. (Copies of annual reports are available.) The 2012-13 report also notes that the increased demand may be regarded as an indication that vulnerable people in the Leeds metropolitan area have been provided with vital IMCA protection at crucial times in their lives.
3. Articulate Advocacy only utilises appropriately trained and qualified individuals as sessional workers to provide independent mental capacity advocacy as Independent Mental Capacity Advocates (IMCAs).

4. Leeds Advocacy and Articulate Advocacy maintain a strong ethos of user and staff involvement in the organisations' work. Therefore, all the IMCAs managed by Articulate Advocacy were invited to take part in a workshop day during which the questions posed in the request for evidence were discussed. Those who could not attend were invited to contribute their experience in writing. This submission is a précis of those individual and collective responses. Eight IMCAs as well as two managers – with more than 30 years cumulative experience – contributed to the discussions in preparation of this submission. The exercise was perceived as an example of a continuing commitment to person-centred care by involving those involved in the day-to-day delivery of IMCA services rather than merely providing a management overview.

5. The chief executive, directors and a number of individual IMCAs are available to give oral evidence to the Select Committee.

6. This evidence is a corporate submission from Articulate Advocacy CIC.

RESPONSES TO QUESTIONS FROM THE SELECT COMMITTEE

Overview and context

To what extent has the Mental Capacity Act 2005 (MCA) achieved its aims? (This was considered in the context of the summary published on the Ministry of Justice website and reproduced as an appendix to this submission.)

Which areas of the Act, if any, require amendment; and how?

At the core of the MCA are its principles and definitions of capacity and best interests. Are these appropriate?

7. IMCAs working for Articulate Advocacy (AA) believe that the Mental Capacity Act 2005 has largely achieved its aims. However, the scope of the legislation – in terms of assuming that everyone has capacity until otherwise established – does nevertheless permit the potential manipulation of vulnerable individuals with limited capacity.

8. Experienced IMCAs expressed hopes that wording in guidance and code of practice documents could be clarified – and made tighter than the current illustrative vignettes – to strengthen protection for such individuals.

9. Concern was expressed that capacity assessment questions were potentially too subjective – and could very easily reflect literacy levels, cultural backgrounds and the values of the professionals.

10. Definitions of capacity and best interests need to be re-defined in terms of “dimension” – as frequently an individual has limited capacity rather than general capacity. These dimensions include the “who, what, when, where, why, and how” questions – in that an individual may have capacity when they are comfortable in familiar surroundings rather than distressed in hospital or later in a day rather than when they have just been woken.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
B. Implementation

To what extent have the five principles of the MCA been implemented in frontline practice? What evidence is available to assess this? Is there a satisfactory balance between enablement and protection?

How effective was the Government’s implementation plan? What measures were taken to ensure that professionals and families of those who lack capacity know about and act in accordance with the provisions of the MCA? Has it led to sustainable change?

Is the Act widely known and understood by professionals required to implement it? How does this differ across different sectors, such as health, social care, banking and others?

11. Understanding of the Act and its scope appears to be directly related to training and individual professional familiarity. The lack of appreciation of the legislation, its scope and implications remains a concern in some areas – such as private care homes and with some parts of the medical profession. The effectiveness of the Government’s implementation strategy therefore remains incomplete and with mixed success. Some healthcare professionals anecdotally report having received MCA training while simultaneously displaying little knowledge of the role of an IMCA.

12. The dominance of the medical model – and an institutional high-handed approach among some older medical professionals to fail to appreciate “best interests” other than within an extremely narrow and short-term context has also impeded the Act’s full and successful implementation.

13. The failure to absorb change appears to be a result of corporate culture within the NHS, with its larger and more hierarchical staffing arrangements rather than in adult social care with local authority management. Greater familiarity with many aspects of caring for vulnerable people in the social care field and the dominance of the social model allows for a more positive approach to person-centred care for people lacking capacity.

14. The hierarchy in the NHS means that junior staff are often very unwilling to step out of line from senior consultants directives but we feel in practise this means that the staff with the closest and most contact with patients who could contribute most to relaying the personal point of view and wishes of that patient is not heard.

15. Levels of understanding of the MCA within the health and care sectors are widely disparate. While many in primary care and dentistry appear entirely unaware of the implications of the legislation, other individuals stand out with great personal appreciation and understanding of the issues and concern for those affected.

16. An (understandable) aversion to risk – perhaps as a consequence to a more litigious external culture, the lifting of restrictions on the commercial activities of law firms – has meant that more medical professionals appear to prefer an approach of continual monitoring of vulnerable patients (with the consequence that they face lives of unremitting boredom) to proper and more appropriate ‘life activity risk’ assessments. The social care model – where practitioners work from the ethos that individuals

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should each “have a life” with managed risk – better reflects a truly person-centred approach to vulnerable people and those lacking capacity.

17. On neurological wards, MCA appreciation seems greatest among nursing staff while some more senior medical practitioners appear unaware of the protection it can afford for them while simultaneously improving care for vulnerable individuals.

18. Nursing staff and hospital managers particularly appreciate the benefits IMCAs can bring indirectly when they become involved with decisions about an individual’s potential change of accommodation – as “bed blocking” issues can be resolved more quickly, because of the additional obligations placed upon local adult social care teams.

Is the Act widely known and understood by those who are directly affected by it and by their non-professional carers? To what extent does the Act provide protection and reassurance for informal carers? Has the right balance between struck between protection of the carer and protection of the individual lacking capacity?

Has the Act ushered in the expected, or any, change in the culture of care?

Is there any evidence that the provisions of the MCA affect some groups disproportionately? If so, what data exists to compare representation across different socio-economic groups, Black and Minority Ethnic groups, and gender?

19. IMCAs repeatedly encounter among (healthcare) professionals a mentality that struggles to cope with the concept that vulnerable people have the right to make “unwise” decisions – a factor which may adversely affects assessments and care planning. This mentality also can make some professionals find it difficult to take in to account that a person’s capacity can vary according to time, location and other circumstances this can also be the case after MCA familiarity training has been given.

20. IMCAs frequently have to remind (healthcare) professionals that capacity assessments should be repeated – in different locations and at different times of day – in order to establish their validity. Frustration also occurs when (healthcare) professionals confuse mental incapacity with other disabilities and limitations – such as an individual’s capacity to speak or communication, when their mental capacity is not at all otherwise compromised. In such circumstances, it becomes clear that the concept and definition of “time and decision specific” have not been understood.

21. Sometimes similarly, in such situations, it becomes apparent that the principles of “best interests” in certain medical environments (including Psychiatry) are being considered solely in a short-term medical context with little recognition of a (vulnerable) person’s longer-term social or psychological wellbeing. This approach appears to reflect a situation that is institutionally over cautious with many of the reasons for this being lost in time.

22. MCA training for many health professionals has clearly been inadequate – both initially and in terms of continuing training.

23. Local dentists’ appreciation of MCA legislation varies from praiseworthy – at a specialist regional centre – to non-existent in some parts of the private sector.
Articulate Advocacy CIC – Written evidence

24. Attitudes of some – senior – medical professionals indicate that they still remain unclear about the provisions of the legislation or the reasons for its enactment. The introduction of compulsory introductory training and continuing education for those being appointed to “consultant” positions would improve the quality care and ease of access for IMCAs.

25. Where positive responses are forthcoming from healthcare professionals, this seems to be as a consequence of contact with the IMCA service and an increasing familiarity with individual IMCAs and the reasons for their involvement when capacity concerns arise.

26. Having a “MCA lead” in hospitals and adult social care in Leeds had brought definite benefits. However, much work remains to be done in terms of training and awareness, especially for medical and healthcare staff.

27. Available consent forms need to be changed – and brought up-to-date. IMCA’s experience in Leeds is that forms available on some wards are still an old version the need for new versions is only identified when they are challenged by IMCAs.

28. Confusion still also occurs in situations where the need to for serious medical procedures are urgent – and medical staff fail to appreciate that the involvement of an IMCA is not necessary in such circumstances – indicating a failure to understand the Code of Practice.

29. Work with informal carers groups locally suggests that such individuals and the support mechanisms arranged for them have not adequately learned about the legislation and its scope. Carers believe – mistakenly – that the act deprives parents, for example, of some of their obligations towards adult offspring.

30. The concept of the “next of kin”, similarly, is not sufficiently appreciated and understood by many – from health professionals to carers and from care homes to other voluntary organisations.

31. Work contact with families suggests a wider misunderstanding of the concept of consent – and widespread confusion between the notions of dignity, privacy and confidentiality.

32. Over-protective parents frequently present problems, especially when they believe that their knowledge should have primacy in establishing the “best interests” of an individual lacking capacity.

33. Slightly more people from ethnic communities are benefitting from IMCA services than the demographic of Leeds would suggest. Longitudinal data has not been collected for long enough to establish any correlation between medical conditions underlying dementia, for example, in these groups and the overall population to determine whether this is a local phenomenon or indicative of service access and referral ease. The local authority is mindful that over representation of ethnic minorities may be a concern rather than a success i.e. potentially a lack of capacity judgement could be seriously flawed and be the result of no professionals understanding or communicating a certain language dialect or cultural viewpoint.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
C. Decision making

Are those directly affected by the Act being enabled and supported to make decisions for themselves to a greater or lesser extent than they would have been in the past? Does the means by which the decision is made – ‘general authority’, Lasting Power of Attorney, deputyship, Court of Protection – affect the quality of decision making?

34. The cost of registering powers of attorney remains a significant concern – not least because of the need to pay in advance for registration at a time when an individual may not have the capacity to release the funds necessary. The “Catch-22” predicament has become a problem.

35. Similarly, the sums involved are a significant deterrent – especially as vulnerable individuals may not have access to sufficient cash liquidity. There may have to be a cost benefit analysis undertaken around the issue of having clarity around an individual’s wishes before capacity is impaired rather than the difficulties in researching intended wishes and second party decisions after capacity is lost. What evidence is there that advance decisions to refuse treatment are being made and followed?

36. Many medical staff do not appear to appreciate that “Do Not Attempt Resuscitation” (DNAR) or Cardio-Pulmonary Resuscitation (CPR) instructions represent decisions regarding serious medical treatment – and, consequently, “due process” may (unintentionally) be overlooked.

37. IMCAs have also encountered circumstances where such instructions have erroneously remained on individuals’ medical files after release from hospital – with potentially disastrous consequences.

Has the MCA fostered appropriate involvement of carers and families in decision-making?

38. Individuals who pay for private residential care may not be looked after adequately if assertive family members are not frequent visitors to ensure that they get the necessary attention and do not fall foul of what is known as “Fawlty Towers” nursing or care.

39. Care for those who have been covered by the MCA is frequently significantly better than that for those who are self-funding.

40. IMCAs say that they are continually learning through doing the work – but the time-limited nature of the work is frustrating. The experience in Leeds is that there is a wish to provide informal on-going monitoring to maintain contact with a vulnerable individual after the IMCA arrangement has ended, specifically because there is nobody else anywhere for them.

41. The development of a “post-IMCA” trained independent volunteer visitor programme would, in such circumstances, not only provide an independent (social) contact for vulnerable individuals, but allow for enhanced longer-term monitoring, to ensure that provisions documented in care packages by care managers, professionals and IMCAs been put into place and consistently implemented.

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42. CQC assessments can be counterproductive – in our experience some residential services provide high quality care and they often do not consider their excellent behaviour management to be out of the ordinary and these regimes enable vulnerable individuals to receive care in ways which do not provoke “challenging” behaviour. Unfortunately because of the poor methodology of the CQC these residential services are rated less favourably than those which do not proactively avoid such “challenging” circumstances for the individuals.

Has the role of the Independent Mental Capacity Advocate (IMCA) succeeded in providing a voice for clients and an additional safeguard against abuse and exploitation for those who have no-one to speak on their behalf?

Has the level of referrals to IMCAs met expectations? What are the reasons for the regional variations in the number of referrals?

Are IMCAs adequately resourced and skilled to assist in supported or substituted decision making for people lacking capacity?

43. Experience of working with people with learning disabilities before the Mental Capacity Act came into effect suggests that – anecdotally – that the legislation has had a positive impact on the quality of care for this particular group of vulnerable people.

44. Two strands of carer and family involvement have become apparent – that professionals involve service users and those around them as a “box ticking” gesture or where, because of the default involvement of the IMCA, the MCA has succeeded in providing voices for clients and additional safeguards against and exploitation. This is particularly apparent in situations where over-dominant or over-protective parents and family members (perhaps unintentionally) abuse individuals by depriving them of opportunities to live their lives as fully as possible or exploiting their vulnerability to make their own lives less challenging.

45. Institutionalisation – even of families and carers – requires consistent challenge, which has implications for time and resources. For example, hospital ward rounds are timed to suit the professionals involved rather than (vulnerable) patients.

46. Similarly, social workers do not take vulnerable individuals – with or without capacity – to visit potential (care or residential) homes when changes of accommodation are required. IMCAs felt strongly that not doing this was compromising the ability of even those with limited capacity to express any sort of view about the available options – and that arrangements should be required (under guidelines or codes of practice) for this to happen, either with social workers, IMCAs, or others with advocacy training or experience.

47. Workloads, especially in the health and care sectors, appear to be in perpetual conflict with the heavier demands of person-centred approaches.

48. While case law – CC v KK and STCC - has provided some clarification of the priorities, pressures on staffing levels continue to inhibit the quality of care available to vulnerable people and those with capacity concerns.

49. Concerns remain about advance decisions – because they are perceived as expensive and unclear. The degree to which informal remarks or writings can be
observed remains confusing and that the value judgements of those responsible for interpreting such wishes can cloud if not entirely overrule an individual’s wishes. (Over) Protective parents and family believing that “they know best” and professionals conceding to this because of as examples media and legal pressure frequently appear to override individuals’ hopes.

50. IMCAs are greatly concerned that those granted powers of attorney are not fulfilling their (legal) obligations.

51. While local authorities and the NHS have – free – access to the Office of the Public Guardian to establish the identities of those whose powers of attorney have been registered (and the nature of those powers), IMCAs and other organisations do not. IMCAs report frequently encountering family members or friends who “think they have” power of attorney or more than one family member who claims to have such powers. IMCAs and organisations such as care homes need rapid and free access to a central register to be able to check the identities of those with PoA.

52. The Office of the Public Guardian should – for example – provide online checking, where licensed care providers and IMCAs can have access to a password-protect and secure website to check the nature and identities of those claiming to have Powers of Attorney. Such requests should be logged using an automated audit trail to ensure compliance with data protection legislation.

53. IMCAs are greatly concerned that while family members and friends appear willing to assume powers of financial attorney, they are far more reluctant to assume responsibility for another person’s health and wellbeing.

54. Those with Powers of Attorney remain confused about the differences between LPA and EPA.

55. IMCAs are concerned that the costs of registering powers of attorney are prohibitive – and are a deterrent to their proper (and probably intended) use.

56. No easy and effective means of policing those with powers of attorney is available. IMCAs have encountered situations where those with attorney make no attempt to contact, let alone communicate with, those for whom they have such powers.

57. IMCAs would like to see an expansion of the role of the Office of Public Guardian to cover policing of powers of attorney – so that attorneys have to provide regular (confidential) reports of how (financial) decisions are made and the expenditure that is authorised. Such a remit would also provide a service where IMCAs could report concerns about attorneys that could be investigate quickly and sensitively. The OPG should also have sufficient staff to make spot checks on those with powers of attorney.

58. Confusion persists about the concept of the “next of kin” and what this means for various organisations, services and professionals. Easy provision should be made for individuals to document “chosen families” who – with the production of appropriate identification – have access to them in hospital, for example, and whom IMCAs and other carers could contact. The mobility of labour over the last few decades, the dispersal of family members and smaller families, as well as difficult family dynamics, all mitigate against the “genetic family” automatically knowing the most or being

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appropriately informed or accessible in order to have any idea whatsoever of another person’s “best interests”. these dynamics seem to be changing at a faster ever pace as resolutions are sought (Inconsistencies in rights of access between civil partnerships and co-habiting couples further exacerbate such potential difficulties as do aspects of Mental Health Act and such as issues as legal status of next of kin within it

59. The introduction of IMCAs, those doing the work believe has succeeded in providing voices for clients and additional safeguards against abuse. However, as the remit of IMCA involvement is time-limited, concerns have emerged about what happens once an IMCA is no longer involved. The sudden end to involvement can exacerbate confusion for people with capacity concerns – because someone with whom they have been obliged to develop a detailed and rapid relationship suddenly disappears. IMCAs feel their (paid) obligations should be extended to allow – diminishing – contact with clients for perhaps six months after the initial involvement. During that time, facilities should be introduced for reports to be provided for the Care Quality Commission (or similar agencies) should concerns (either about the individuals or care or residential homes, for example) become apparent. IMCAs feel they frequently notice small, but vitally important, aspects of care which social workers or nurses do not (have the time to) see, especially about the quality of life for vulnerable people.

60. IMCAs remain concerned that some of those managing health and care services can make assumptions about “older” people which are increasingly irrelevant and appear distant and rooted around the middle of the last century, particularly around aspects of life such as tastes in music, clothing, entertainment and décor surroundings. IMCAs fear that many accommodation providers – especially corporate conglomerates – give far greater priority to the “front of house” appearance of their premises without anywhere near adequate acknowledgement of the need for job satisfaction among their employees (especially among those who are lowly paid) at the cost of appropriate person-centred care for those who (are often personally) paying for such services.

61. IMCAs are keen that care reviews scheduled for six weeks after changes in accommodation should be mandatory, also that annual reviews should mandatorily include IMCAs.

62. IMCAs reported that frustrations were emerging about the degree to which reports could be directive. Options could be identified and documented – but they felt constrained by the degree to which they could influence decision makers in the directions which had emerged as truly representing the “best interests” of a person lacking capacity.

65. IMCAs also felt that – even though their contact with such individuals was time-limited; they often achieved a good rapport, especially if the client could appreciate the independence of their role. Such involvement also put them in positions where they regularly observed a dilemma facing care staff who on the one hand tried to be person centred and on the other hand needed to plough through an often very high work load.

66. IMCAs also felt that far more referrals – for capacity assessments – should be forthcoming (pro rata the population) from an area with the population of the Leeds metropolitan district.

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67. IMCAs felt that the “sessional” contracts of employment commissioned in Leeds allowed greatest flexibility for IMCAs and allowed a “bolder” approach to working with health and social care providers than may otherwise have been possible (the local “sessional” approach covers remuneration as staff members on a payroll – including holiday and pension provision).

68. IMCAs reported that – in Leeds – they felt that the service had, over five years, developed a “mature” relationship with the Leeds council’s adult social care department, who welcomed referrals and had understood the “quality control” aspect of the provisions for litigation far more positively than informal reports and contacts with IMCAs from neighbouring services suggest exist.

D. Deprivation of Liberty Safeguards

Are the safeguards in the Deprivation of Liberty Safeguards (DoLS) adequate?

Are the processes for authorisation, review and challenge of DoLS sufficiently clear, accessible and timely?

69. IMCAs reported that the origins of the concept of “deprivation of liberty” in the legacy of the “Bournewood situation” had helped but there was still far many people with a learning disability without family “voluntarily placed”, deprived of their liberty in mental health institutions but not under the protective framework of DOLS legislation or the safeguards they would receive from a formal mental health section.

70. While some case law was now emerging, the lack of clarity appeared greatest in hospital and when individuals without capacity had to be transferred between accommodation.

71. The background of Leeds IMCAs in the voluntary sector and in working with people with learning disabilities had, they said, provided a perspective that proved useful in these circumstances.

72. The IMCAs reported that, frequently, they felt that some individuals “came off” DoLS not because they understood why they needed protection but because they passively acquiesced rather than an active challenged restrictions that had been placed upon them.

73. Similarly, checks and balances on the way restrictions are allowed were inconsistent – with decisions being made by one individual where we feel it should be a group decision.

In other quasi-judicial settings, decisions have to be taken by more than one person; magistrates sit in threes as do appeal court judges. DoLS restrictions should only granted by panels of three whose decisions are documented and made publicly available (within constraints of confidentiality, possibly with redactions where necessary).

74. IMCAs reported that the processes for DoLS could be significantly improved – not least because the paperwork was very unclear, especially for use in hospitals or when time or other pressures were great.

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75. Concerns were also expressed that some DoLS constraints had remained in place for as long as three years without adequate reviews. The establishment of small “core groups” involving IMCAs, care managers and (residential) home managers for regular monthly meetings was letting progress be monitored for some individuals in and around Leeds.

76. Some DoLS IMCAs also expressed concerns over whether they were acting as RPR “relevant person’s representatives” or 39C or 39D of the Act – because of quick crossover of roles they were potentially confused about the difference in each role, its rights and responsibilities, and that Managing Authorities have been very unclear about these aspects.

77. As with powers of attorney, no provision seemed to have been designed for policing RPRs, their work or effectiveness, or requiring accountability through transparency. Those who – as RPRs (often family members of the person with a professional background) were most familiar with the regulations and were most assertive could easily overawe (or even bully) health and social care professionals into allowing them primacy, regardless of the true best interests of a vulnerable individual.

E. The Court of Protection and the Office of the Public Guardian

Are the Court of Protection and the Office of the Public Guardian sufficiently understood and accessible to all? Are they operating effectively and successfully?

What has been the impact of the introduction of Lasting Powers of Attorney (LPA), especially with regard to decision making on matters of personal care and welfare?

What concerns, if any, are there regarding the costs associated with registering an LPA, or with making an application to the Court of Protection?

Is legal aid available and sufficient? What impact will the recent and proposed reforms to legal aid have?

78. IMCAs expressed that they were pleased they could take on the role of litigation friend because they are local and can keep discussions and cases centred on a person’s needs and wishes rather than a case sometimes centring around legal points of order between opposing law teams. IMCAs however are quick to praise some law firms (often characterised by individual lawyers who had developed a personal interest had expertise in this area and were client centred), they are equally fast to identify and criticise lawyers who appear to fail to perform adequately. Circumstances were identified where individual lawyers had made no attempt to contact IMCAs, individuals’ families or friends about an individual without capacity or where lawyers (who were charging and being paid) had effectively asked IMCAs to do their work for them and there is also a concern that lawyers have a vested interest to keep a case open, possibly feeling resolution is not a good thing (for them).

79. IMCAs have encountered situations where the official solicitor has appointed law teams from for example Newcastle nearly a hundred miles away from Leeds making personal communication and meeting of clients more difficult and not person centred.
80. The complexity of potential costs around someone with capacity concerns regarded with continuing apprehension and not least with regard to the practicalities of having access to money – because cash is needed “up front” for applications to the court at the same time as a person without capacity does not have the scope to authorise any payments or expenditure. This other “Catch-22” dilemma needs rapid – and realistic – resolution.

81. The roles of the Family Court and the Court of Protection also need to be more clearly defined, as resolving potential confusion about which has jurisdiction frequently take too long and cost too much to resolve, as this process can further compromise the wellbeing of a vulnerable individual.

82. Also, where individual solicitors are named to have powers of attorney, problems arise when they leave particular law firms. The regulations need to be revised and clarified so that individuals should nominate legal “practices” or firms or successor firms rather than individual lawyers.

83. Conflicts have arisen where two individuals granted powers of attorney have been in conflict. Procedures regarding priorities in such circumstances require rapid clarification. The use of joint powers of attorney – recommending both lawyers and lay individuals, perhaps with a minimum of three – so that legal fees are only incurred where genuinely necessary and that appropriate majority decisions can be reached (and documented) to ensure optimum “checks and balances” in the interests of vulnerable individuals without capacity.

84. IMCAs (who are acting as litigation friends) reported being impressed and reassured by the calibre of judges sitting in the Court of Protection in Leeds – and the sensitivity displayed towards the circumstances and needs of vulnerable people. They hope this standard can be maintained.

85. IMCAs similarly reported that they felt room for improvement exists in the attitudes of some barristers and solicitors towards litigation friends, whom they appear to perceive as “laity” and emotionally involved (even prior to meeting the IMCA). Standards have improved but the quality of service still remains highly-dependent upon the calibre of individual lawyers.

F. Regulation

Is the role of the Care Quality Commission in inspecting on the MCA standards adequate and appropriate? Is there a case for additional powers?

Should other regulatory bodies, such as health and social care professional regulators, be acting in this area?

86. The Care Quality Commission is regarded as understaffed, weak and taking too long to publish its findings, so that its findings may well be out of date before they reach the public.

87. Similarly, the failure to balance appropriately planned and surprise visits undermines the Commission’s potential effectiveness.

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88. Cutbacks to Commission staff and its remit are a concern.

89. Some IMCAs perceive the CQC as considering care homes in particular as “machines”, examining how they ‘function mechanically’ rather than how the organisation, management and staff provide services that relate to the principles of person-centred care. The CQC has not given any indication that care plans are being met – and this is seen as being a primary role of any quality control monitoring. Also, CQC’s standards criteria – especially with the use of terms such as “adequate” are regarded as bland and meaningless.

90. IMCAs felt strongly that they – or other independent external assessors – should have means to highlight concerns with the CQC or local authority adult social care services (in confidence) so that unannounced inspections can be made.

91. Public comments made about care homes and hospitals should be published (with appropriate moderation for inappropriate language or defamation) on the CQC or a similar website.

92. Local authorities check IMCA services through regular reports and meetings with commissioners and/or contract managers to ensure compliance. Feedback reports from decision makers are sought at the end of each case – extracts or published by Articulate Advocacy in each annual report.

93. IMCAs in Leeds believe they have achieved a “confidence threshold” where, especially through the use of litigation friends, they regularly and repeatedly demonstrate their independence from health and social care organisations and where IMCAs, individually and collectively, have acquired the confidence to challenge professionals. They believe they strive to work collaboratively, with their own professional maturity, as far as possible but are not overawed when circumstances indicate that “going to law” cannot be avoided.

94. IMCAs reported that in some neighbouring local authorities IMCAs did not feel able to take on the role of Litigation Friend. However, IMCAs in Leeds reported that in some of the cases where they acted as Litigation Friend it was actually the local authority that had instigated and paid for this.

95. Reservations were expressed that the local NHS ambulance trust had not fully appreciated its MCA responsibilities – leaving the police, by default, to become (unnecessarily) involved in the transfers of people without capacity between accommodation.

96. IMCAs are still concerned about the lack of clarity between the NHS and local authority around mental capacity and mental health legislation and local authorities’ scope for charging for care. One case was cited where a person was where she did not want to be – but she was being charged for that accommodation against her will. She was being charged a second time for the legal services necessary for an appeal (without her cognisance of this) and without being aware what was happening. IMCAs are concerned for her wellbeing when she recovers capacity and discovers what has happened.

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Articulate Advocacy CIC – Written evidence

97. IMCAs expressed annoyance about the lack of “expandable boxes” on the web pages used for electronic DoLS documentation. They believe they should be able to submit reports ranging from either 50 words to 5,000 words (if necessary) without having to lose additional electronic files as these can be – and have been – separated and lost, causing unnecessary and avoidable additional difficulties and delays.

How well is the relationship with the mental health system and legislation understood in practice?

98. Experienced IMCAs, with mental health experience, expressed concerns about the (over-) complicated juxtaposition of mental capacity and mental health legislation obligations – and the division of responsibilities between local authorities (over guardianship, for example) and the health service (over sectioning), especially where capacity is also involved. Such potential conflicts and confusion have become particularly apparent in dealing with people with learning disabilities – and concerns have emerged that similar circumstances may face (increasing numbers of) people with dementia.

99. Conflicts between the medical model of psychiatry and the social model of person-centred care are also frequently encountered, especially with regard to relatively careless use of the expression “best interests”, as this may reflect situations where short-term medical expediency may not be consistent with an individual’s longer-term psychosocial wellbeing.

Additional observations

100. IMCAs reported that they felt that every case was a learning experience and, in Leeds, through the supervision procedures that had been established, formal and informal, individual and collective, they had opportunities to reflect on each and draw lessons from them. Coming together to talk about the Select Committee’s questions had also elicited some concerns about the way some information and experiences are shared – and further work will be undertaken to try to improve local information management still further.

101. However, concerns were expressed that the competitive environment – where local authorities award IMCA service contracts by open tender – did inhibit collaboration and that (commercial) confidentiality or risk aversion in the context of data protection inhibited wider information sharing and the more rapid establishment of collective wisdom and memory.

14 August 2013

Appendix

MENTAL CAPACITY ACT 2005 – AIMS

The Ministry of Justice website says:

The Mental Capacity Act provides a framework to empower and protect people who may lack capacity to make some decisions for themselves.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
The Mental Capacity Act makes clear who can take decisions in which situations, and how they should go about this. Anyone who works with or cares for an adult who lacks capacity must comply with the MCA when making decisions or acting for that person.

This applies whether decisions are life changing events or more every day matters and is relevant to adults of any age, regardless of when they lost capacity.

The underlying philosophy of the MCA is to ensure that those who lack capacity are empowered to make as many decisions for themselves as possible and that any decision made, or action taken, on their behalf is made in their best interests.

The five key principles in the Act are:

1. Every adult has the right to make his or her own decisions and must be assumed to have capacity to make them unless it is proved otherwise.

2. A person must be given all practicable help before anyone treats them as not being able to make their own decisions.

3. Just because an individual makes what might be seen as an unwise decision, they should not be treated as lacking capacity to make that decision.

4. Anything done or any decision made on behalf of a person who lacks capacity must be done in their best interests.

5. Anything done for or on behalf of a person who lacks capacity should be the least restrictive of their basic rights and freedoms.

21 August 2013
AS – Written evidence

The following paragraphs are the corresponding answers to questions hopefully in numerical order, as outlined in your enquiry

OVERVIEW

to what extent has the MCA achieved its aims?

1),3) It is deplorable that appointed officials could honestly make claims that they are truly acting in the best interest of their client, when in reality this is not the case, that their administration has only resulted in the unfair and systematic erosion of the patient's financial assets and much to the detriment of the patient's physical and mental well-being. This present arrangement ought to be viewed as the antithesis to the Government's plans on safeguarding the patient from such a scenario. Please allow me to explain further.

Following an official application to the COP and in order to release funds for the purchase of a property, the medical Consultant Specialist was required to make a professional opinion on the above matter, and is quoted as describing this particular case as a "travesty of Justice". (case reference S2A/11416392). How a patient be allowed to suffer sub-standard living conditions over a seven year period is indeed questionable. While the Deputy having absolute power over property and financial affairs continued to cause much anxiety to the very people who are at the front line of the care and support of the patient. Having originally become homeless due to IHTax demands on the patient, no plans were made at the time by the Deputy to arrange any for funds other than rent money to be invested into another property. Failure to act out his duties at such a crucial time has resulted in causing a considerable amount of suffering ever since. Considering that the patient is from a working class family, had greater significance, with life changing possibilities for the patient in question, but her legacy was never utilised as intended. Instead, a large sum of money has since went missing (£50,000) The Deputy has refused to account for this, explaining that he "has a duty of confidentiality" towards the patient. Despite numerous requests for transparency, the Deputy has never once provided a summary of legal fees that were charged to his client. Furthermore, the Deputy's manner while in office has on occasions been quite offensive and insulting while being confronted.

2) Proposed Amendments: present system lacks fairness and a correct balance should be reached that is built on a democratic framework allowing families and Social Workers to have more say and proactive within the process. The procedure ought not to be bundled onto one person to act as a Deputy who sometimes and quite inadvertently, the Deputy, has to follow inappropriate guidelines. Should a Deputy arrive at a decision that is not in agreement with those personally involved, there is no fair provision available for an appeal to be made because of the legal fees incurred, and time taken for a response. This alienates the conflicting parties to such a degree that the Deputy becomes ever more unapproachable and any positive measures that need to be taken with respect to the patient's physical and mental well being become thwarted and replies made by the Deputy using incomprehensible legal jargon. It is hoped the Court is in agreement that this situation is arguably most counter-productive.

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Implementation

4) 5) "Anything done or any decision made on behalf of a person who lacks capacity should be the least restrictive of their basic rights and freedom"

It is hoped the explanation listed in 1) and 3) above is ample proof that flaws in the system do exist and are not being implemented as in the case being outlined and there is written documentary evidence available to verify this.

6) It can only be assumed that only the persons affected by Receivership issues have any knowledge relating to the Act and true meaning not properly understood by the general public. When given absolute power over the property and affairs this also gives rise to autocracy and the restriction of basic rights and freedom that also affects main carers that support the patients in their everyday lives.

8) Pointless house calls, expensive home visits are ineffective in monitoring and assessments on the quality of life, because of the expenses are non existent

Decision Making

10) 11) 12) please refer to 1) 3) above
13) there is no active Advocate as far as we are aware that the family could depend on to voice any concerns and feel no support is given towards this aim.
14) please refer to 8) 1) 3)

Deprivation of Liberty Safeguards

17) most unsatisfactory response from appointed officials

The Court of Protection and the Office of the Public Guardian:

18) are they effective? - absolutely not! having very little or no faith on their support structure. Any previous attempts to contact and report concerns and complaints relating to mismanagement issues have all been brushed under the carpet as it seems it is in their own best interests to guard the incoming revenues being generated, regardless of the needs of the patient, they persist in adhering to inappropriate protocols and procedures that directly violates the basic rights and freedom of the patient.

19) the impact of Lasting Powers of Attorney Legislation has proved to be a disaster to put it mildly, that is deeply affecting the carers who actually support the patient in most difficult circumstances.

20) the realisation that complaints and appeals are fruitless, and charged out of the patients' remaining funds which continue to decline, as the years go by, without any resolve becoming increasingly frightened by red tape and faceless bureaucracy rampant within the system.

21) there is no legal aid available. and to date, no support given by the Solicitors Regulatory Board. Presumably, there is no one able to contest the COP and taking legal action is beyond the pocket of the carers who continually struggle with existential

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demands and the ever increasing cost of living.7

Regulation

22) there seems to be a missing link between Care Coordinators and the Deputy, as far as we are aware if such a link does exist is certainly kept a secret.

23) Yes!! all available official bodies need to work proactively

26) As the main carer, I will be retiring from active employment within the next 3 years and planning to spend time abroad with my wife, referred to here as "the patient." Plans to provide a better quality of life in a warmer climate have also been rejected by the solicitor acting in the best interest for my wife.

23 July 2013
Asist, POhWER, VoiceAbility – Oral Evidence (QQ 106 – 125)

Evidence Session No. 5    Heard in Public    Questions 106 - 125

TUESDAY 23 JULY 2013

Members present

Lord Hardie (Chairman)
Lord Alderdice
Baroness Andrews
Baroness Browning
Lord Faulks
Baroness Hollins
Lord Patel of Bradford
Baroness Shephard of Northwold
Lord Swinfen
Lord Turnberg

Witnesses

Steve Gray, Director of Operations, Asist, Elyzabeth Hawkes, Regional Manager, POhWER, and Jonathan Senker, Chief Executive, VoiceAbility

Q106  The Chairman: Good morning. Thank you for attending. As you are aware, this is being webcast, and you will be given the opportunity to correct the transcript. If anybody wishes to take their jackets off, feel free to do so because of the heat.

Could I start by asking each of you in turn—I will start with Mr Gray, unless anyone is desperate to start—whether you could give us examples of the type of cases that you deal with as providers of independent advocacy services? What tools do you use, and to what extent do you adapt your approach to deal with different types of impairment?

Steve Gray: Thank you, Lord Chairman. Of course you are aware that there is obviously a range of duties and powers that IMCAs are instructed around. We actually act on all the powers and duties—so change of accommodation, serious medical treatment, safeguarding and care review. Basically, we act on the whole range of IMCA referrals.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
As regards communication, as you are aware I am sure, communication is the key—the cornerstone—of what advocacy is about. Advocacy is fundamentally about someone expressing their views. In this instance, it is for reasons of capacity, but fundamentally it is about communication—so communication tools are at the core of what we do. Advocates are very experienced at using different tools and different ways of communicating, be it pictures, be it using visual stuff, be it using a range of techniques that we use. We have also developed a toolkit for advocates that enables them to communicate with service users and tries to aid that communication. In essence, the most important thing for advocates is to try, in the situation, to find out a way of communicating or developing a way of communicating—to make all efforts to try to find a way of communicating with the service users, to get their view. Even if somebody, in this instance, may not have capacity, it does not mean that they have not got a view, and we are very keen to see that view in the decision-making process.

Elyzabeth Hawkes: Obviously there are the issues that Steve has already covered, in terms of change of accommodation, serious medical treatment, safeguarding and care reviews, but there are also ones specifically in relation to deprivation of liberty safeguards. That needs to be seen as a very important, essential and separate part of the whole process. I think in relation to the communication, we do have the adaptive toolkits that we use, but we also try to build on what someone’s communication style might already be—if they have been in a certain life situation when they have developed different ways of communication, particularly non-verbal. People think that just because somebody is non-verbal, they cannot say what they want, and that is not true; they can. They can use pictures; they can use words; they can use symbols; there is Makaton—even down to the basics of using proper translators, proper interpreters for people who are deaf, to make sure that people get the best opportunity to communicate in their way. Only when you have exhausted all that, we use a thing called a talking mat which is about building up somebody’s own personal toolkit to help them to communicate.

Jonathan Senker: I entirely endorse everything that Steve and Elyzabeth have said. Similarly, we work with people across the broad range of decisions to which people are eligible, either under the mandatory or the discretionary powers. We work with about 2,400 people each year, broadly mirroring the national findings in terms that were shown in the fifth annual IMCA report.

I think Steve and Elyzabeth have covered well some of the issues around communication, and that is absolutely at the heart of how we work. I suppose the other element is about the overall approach that we take and the number of visits that we make. Particularly if we are working with people whose capacity may fluctuate, it may be important to see them in different ways at different times, and use the advice that we may receive on how the person communicates from people who do know them well, albeit they may not be able to independently support people. To some degree, the work of an IMCA can be a little bit like a detective, reaching back to say, “What are this person’s past decisions? What are their past views?” profiling that person’s life to help that come alive for decision-makers. The extent to which we can do that is quite bound by the resources within the service.

I think the other thing to emphasise is that, whilst every person that we work with and every decision that we work with is potentially life-changing — IMCAs do not tend to get involved in issues that are superficial or peripheral — the depth of involvement can
vary enormously from people where their wishes are very clear, the decision-making processes are relatively straightforward and the issues are relatively uncontroversial. At the other extreme, we have had issues that have involved protracted work with the Court of Protection, a good deal of controversy and a good deal of disagreement, or literally life and death issues, quite frequently around “do not attempt to resuscitate” orders. It is important to understand that breadth that there is within the IMCA service also.

Q107 The Chairman: It is difficult to generalise, and you have spoken about the breadth of the cases you deal with, but can you give any indication of the number of visits that you would be involved in at one extreme—the most extreme case? Presumably in the easiest cases, it might just be one or two, would it not?

Jonathan Senker: That is correct. In the most straightforward of cases, where people’s views are very clear, where there is little contention around the outcome, it may be just one or two visits. At the longest, it may be protracted over many months and involve perhaps eight or 10 visits. I can come back to the Committee with some more detail on that if that would be helpful.

The Chairman: You mentioned also that you were bound by resources. Everyone is bound by resources, but do you find that the resources are available for the more difficult cases?

Jonathan Senker: We need to make a balance and manage the resources that we do have. Overall, there is always more that we could be doing to enable the person’s views to really come alive so, yes, we do feel that there is quite a limit on our resources and the time available and that is while we are focusing on just the referrals that we have. With more resources, we could make sure that the service was better known and that access to it was much better. We are very concerned by the differential rates of referral to the service. We recognise that the sole responsibility for making people aware of the service and of their statutory duty should not lie with the IMCA service alone. However, we are also very conscious that IMCAs do, in effect, often act as the main ambassadors for the service on the ground. We feel that there is a great deal more that we could do, both working with people individually but also ensuring that people have access to their statutory rights.

The Chairman: Mr Gray, Ms Hawkes, do you have anything to add as supplementary?

Elyzabeth Hawkes: Just one point: the amount of time that an IMCA can spend with a person to try represent them fully is also tied up very much in the timescale either of a deprivation, a medical intervention or a change of accommodation. That is where, in relation to better knowledge from the people who are in a position to make the referrals—the decision-makers—more proactive involvement of an IMCA gives that advocate the best chance that they can possibly get to do that work. That comes back to Jonathan’s point around the amount of services that we now deliver that do not necessarily have a funded element of awareness-raising, of training and of going out and promoting a service. Historically, that was an integral part of the specification for the contract. Those two things impact on the number of referrals, the real working knowledge within health and social care professionals, and subsequently our ability to be able to do the best we can for that person.
Q108 Baroness Browning: I think you have answered the first part of my question, and that is that you have all confirmed that you deal with people with special needs and people with communication difficulties. But how do you deal, for example, with people either with a learning disability or on the autistic spectrum, or perhaps sometimes both, where actually trying to find out what their view is and what their preference is can be very difficult? Sometimes they will automatically go with whatever is suggested first, in order to be seen to be helpful and willing—and to end the conversation, really. How do you deal with that? Are there enough specialists? I do realise there is a certain regional specialism in some of your organisations. Just looking more broadly, are there enough people with those sorts of specialisms, and are there areas of the country where you can identify that the IMCA service is not working as it should because there are not enough people with those specialisms? Sorry, it is a rather difficult one to bowl to you—to answer for the whole country.

Elyzabeth Hawkes: I think between the three of us we have got a relatively broad coverage. From my own experience, in the areas where we provide IMCA services, there are substantial opportunities for our advocates to gain those specialist communication skills—so not just broad non-instructed advocacy, but actually linked to specific groups. That, again, is a resource issue for us, but over the last two years the skills of the advocates to do that have increased, plus, there are organisations out there who specialise in those particular areas, so the best way to work is within partnership. The chances are that that person may well have had a community advocate that has worked with them in the past, or a member of the family who it is not inappropriate to consult—that we can work with to try to get that whole approach. But we have had many instances where the IMCA has worked in partnership with the person, and with their support mechanism—that is not necessarily family—and then we access specialist skills through the national advocacy qualification and then, supplementary, from specialist organisations around the country.

I would not say there was any real requirement when we are commissioned for IMCA services to actually have to demonstrate that and be really robust about how they can prove that that is a good qualification. There is no form of regulation, for example. That would be a way forward in allowing an assessment of what a good qualification is, what a good training course is and what the right method is. Then that could be personalised to the person, but I still feel that it is very random among different organisations across the country.

Baroness Browning: Thank you. That is very helpful.

The Chairman: Mr Gray, do you want to add anything?

Steve Gray: I can only reiterate some of the points made by Elyzabeth there, really. I will talk about our service. Obviously, we have a range of skills—a range of advocates who we employ for their skill base and their value base. We have a range of people who have specialisms in certain areas, so we draw on those skills. When you are an organisation with a generic team, or with different advocates who are not just IMCAs—they are generic advocates—there is also a resource there that you can use. If somebody is working on a particular case and somebody has a specialist, you can use those people who actually understand that issue. I agree. I do not think there is a particular need for specific advocates needing to be trained in specific areas; I think it is
about all advocates really having a general understanding of all the issues and being trained appropriately.

Jonathan Senker: I think Steve is absolutely right that the mandatory training is available, but it provides a floor rather than a ceiling for the level of understanding that people need to have. It does cover communication. It does cover, to an extent, some different specific conditions, but not the depth that is needed. For us, it is very much about ensuring that each individual has a personal development plan that builds on that.

I know the Committee received evidence previously about gaps in provision and providers needing to draw people in, partly where there is a dispute from people who are placed out of borough. That is unfortunate. The Mental Capacity Act is very clear that it is about where it is that the person lives. I am not, however, surprised that sometimes local authorities may wish to pass on the responsibility to another or to dispute it. There are also many, many examples—perhaps it is something that we will come on to in our discussion—of where advocacy is needed, including for people who may lack capacity in relation to particular decisions, and yet the statutory provision does not cover that. In terms of the availability of people with specialist skills, it is very much up to the individual advocacy organisations to ensure that that is in place. I do not think it is sufficiently monitored and evaluated. We know from people who have joined our organisation from other organisations that sometimes there is quite a key gap that we need to address there.

Q109 Baroness Andrews: Can I probe a bit more? One question—a simple question, perhaps—is: what sort of range of people come forward to be IMCAs? What are the parameters? Secondly, when you talk about the nature of training—Liz, you have talked about the possibility of a professional qualification, something that would institutionalise what sector skill would that link to? How could that be institutionalised? Would it be generic training? Obviously, it sounds as if communications runs across the training programme. Can you see differential elements of progression within a training programme like that? Thirdly, in relation to the geographical lottery, perhaps, is it the absence of the ability to recruit which is reflected in that? Is that lottery something to do with the absence of the professional skills or a commissioning issue, which we will come on to later?

Steve Gray: With regard to who become IMCAs, it is a very wide range of people. It is potentially people who have an interest in social care and a very sound value base about why they want that job. From our point of view—how we recruit in our recruitment processes—we do not ask for any particular qualification. It is fundamentally about values and skills, and past experience is the key. Having said that, a lot of people who come to us for a round of recruitments have, for example, social work qualifications or nursing qualifications. So it is very broad on who it actually attracts, but generally it is obviously people who have got an interest in social care.

With regard to the qualification, there already exists, of course, the independent advocacy qualification, which has varying elements to it. Of course, you specialise in IMCA if you want to work as an IMCA, or in DOLS if you want to work in a DOLS area of the work. Then the general generic advocacy is part of the qualification of advocacy for people with adults or learning disabilities. So the qualification framework already exists; that is there and is in place. As an organisation, I have a training arm, and we are able to provide that training in-house to our advocates, and to other organisations.
outside our organisation. The qualification is there, and it does offer a range of training within that.

Taking Jonathan’s point earlier, whether more in-depth training around specific areas needs to be looked at is another issue. Again, I think that links in with the idea that it is left to the organisation, very often, to meet any gaps there in the training.

Jonathan Senker: Perhaps I should pick up on the last part of the question, which is: if there is a gap, is that to do with recruitment or with commissioning? I am impressed by the people who come forward for these roles, given the very strong skills mix that is needed. We need somebody who is comfortable sitting on the floor with a young person with learning disabilities, finding a way to communicate, and somebody who is comfortable challenging decisions including quite often in situations with a high potential for people to be adversarial, and to do so in a negotiated and calm way.

I think the critical issue is not recruitment; it is commissioning. I know that we are going to come on to that and the Committee will want to ask more around it. Particularly, the way commissioning is at the moment, it very much focuses on the amount of time that is spent directly in contact with people using the service, or on their behalf. That is incredibly important—we do not want people sitting in the back office—but it does not necessarily make it as possible as it should for organisations to afford the training and the supervision necessary to ensure that people continue to develop their professional skills and abilities. It also means that there is a very tight squeeze on the salaries that we can afford to pay people, and it can mean that people will move on after a period of time to other professions that may be better remunerated than independent mental capacity advocacy tends to be.

Elyzabeth Hawkes: Just adding to Steve’s point about the sort of people who apply for IMCA roles: it is health and social care professionals, but there is also an amount of people who have perhaps spent their time working with vulnerable people in housing situations, and who are particularly strong around human rights and what people are entitled to. It is that background of the right ethics, morals and principles that is what you need to be able to build on, with somebody who is strong and can stand up for the person they represent—so quite tenacious. They do not necessarily have to have a qualification to be able to do that. The issue around the qualification that we have got at the moment is, as Steve said, that we all deliver that module. We deliver it by affiliating with different organisations, and I think we deliver it to the best of our ability, but there is no national standard. So you could do a qualification with X, and although the modules would be the same and the qualification would be the same, there is no guarantee that what you have to produce—the sort of evidence you did, what you were observed doing—would meet the same standard as the person who did it with Y. That is the issue—that there is no standard. There is quality, but it is not measured across the board. We all have external quality marks, and they look at that, but if I chose to I could set up in business as a deliverer of a national advocacy qualification, and hopefully my outcomes would be very good, but I would not necessarily be as good as the person sitting next to me, and there is no way to ensure that.

Baroness Andrews: That was very interesting. Thank you very much.

Q110 Lord Turnberg: I was struck by how much overlap there is between the sorts of activities that you perform in your different organisations. Presumably you have
advocates working for you who have similar qualifications dealing with similar clients, and you mentioned that there are other organisations out there. So the question really is: how does someone out there know whom to approach? Why would they come to you rather than you? Is it a bit confusing? Do you not work together, or are you in competition with each other? Can you describe the interactions?

_Elyzabeth Hawkes_: I think from my point of view the people referred to an IMCA service would have a provider for their local area commissioned by their local authority. That would be the statutory provider for the county or the borough. That is very clear. For IMCA, the way it is commissioned is—as Jonathan said—where the person is placed. It does not matter where their funding comes from; it is where they actually are at the time. So for that geographical area, you have an IMCA provider. That is relatively clear, I think, and that is how we bid for services.

We are in competition with each other. If a local authority tenders for an IMCA provider in a London borough, we could be in competition with each other. We would go through a competitive tendering process, answering questions about how cost-efficient we were and what the quality of our service was, demonstrated by our quality marks and examples of our casework. But I also think that we can work in partnership as well, because sometimes you will have an area that has, say, Asist being an IMCA provider where VoiceAbility might be providing IMHA, and POhWER might be there doing community advocacy for people with learning disabilities. That is when I do think that we are able to work together to make sure that that person gets the best support. But there is always going to be competition there.

_Lord Turnberg_: So it is partly geographic—

_Elyzabeth Hawkes_: Yes.

_Lord Turnberg_: —and partly competition provoking you into high-quality provision of care.

_Elyzabeth Hawkes_: Potentially, and the desire to provide a good service, obviously.

_Jonathan Senker_: I would like to think that competition provokes high quality. That does depend, though, on the determinant of who is awarded contracts being one of quality. That requires that it is the most important thing over price, and that the people making that commissioning judgment have a good register of what a quality service is, which some local authorities are better at than others are.

_Lord Turnberg_: We will not go into whether competition is a good thing in this area or not.

_Q111 Lord Patel of Bradford_: I just want to take you back to something that Baroness Andrews said about the quality of the IMCAs. Clearly, your IMCAs are very skilful and experienced people. What I am interested in is the other people that help the IMCAs, because we said earlier that you have interpreters, whether for different languages or Makaton. If I give you an example, then you will see what I am getting at. When I was a social worker, ASWs were using Asian interpreters. There were two big problems. One was that one of the Asian interpreters had never ever been trained in or understood what a section was or what a mental health issue was, so they would turn
up completely blind in a situation where somebody was throwing TVs out of the bedroom window, and so would say, What happened there?”. Secondly, because of the anxieties about so-called cultural knowledge, we had the interpreter’s view of what the assessment was, as opposed to the ASW’s. What do you do with people who help IMCAs? Has this come up? Is this an issue at all?

**Steve Gray**: Personally, it is not an issue that we have come across very often. I agree that interpretation in advocacy is always a problem. Advocacy is very much about the communication between one person—a service user—and the advocate, and things can be lost in interpretation. When you are working with interpreters, that disconnect does cause some potential issues sometimes between the advocate and the service user. But, unfortunately, if you do not speak that language you have to use some kind of method to be able to communicate with the person.

Sometimes we are fortunate to have people we are working with in the organisation who may speak a number of different languages, and that is something that we find quite useful, because it means we can draw on that resource. It is an internal resource, and they have an understanding of advocacy and understand what the process is. In that situation, that negates some of those factors. I guess in situations where you do not have that resource internally, you have to go outside. I think it is about being aware of that when you are working with an interpreter and being doubly sure that you are getting it right and are hearing correctly.

**Elyzabeth Hawkes**: I think also, to support that, in the areas that we work in we build various relationships. In some advocacy organisations there are deaf people who are advocates, or people who speak a certain language that are advocates, which is always an added benefit. But if we work in an area and look to build a partnership with a particular translation service we would, before we agree to use that service, provide it with some local induction into what we did so that it had the knowledge to be able to interpret appropriately. I think that is a case of testing the market and seeing who is a good-quality provider, and building that link; and then also using the person’s own system of interpretation, which they potentially have as well, if that is what they are comfortable with.

**Q112 Lord Faulks**: Good morning. I declare an interest as an advocate but an ordinary advocate, as it were, unlike an IMCA. I have to represent people even if I do not agree with their course of action, if they require me to do that. You have a rather different role sometimes. On occasions, you will be supporting the client to make the decision and respecting their wishes. On other occasions, you will be representing their best interests but not necessarily following their wishes. Now this is an acutely difficult choice, I suspect, sometimes for you to make and to reflect your role. Do you think there is anything in the Act—of course, we are scrutinising the Act—which could be improved so as to make that distinction clearer and more helpful for you?

**Jonathan Senker**: It is a really important question. It goes to the heart of how IMCAs work. We have found that the interpretation of the Act is broadly consistent—that our focus is on the person’s views and wishes. We are also providing an additional protection for that person by making sure that the decisions are taken in line with the Mental Capacity Act. That does take good judgment. It does take careful supervision.
I think it is interesting how the Mental Capacity Act and the IMCA service works in practice. I shall give you an example of two women in neighbouring hospital beds. Both of them have advanced dementia. Both of them are very clear that they want to return to their own home. For one of them, quite unusually unfortunately, everything possible has been done to support her in her own home previously. People have gone to heroic measures to enable that to happen, and it has led to some very poor results for her, and there is nothing that people can think of that might change that. The woman in the neighbouring bed has not had that support and is more typical of many of the people that we work with, where there is almost a default choice that if somebody has quite advanced dementia and is finding life rather difficult—if there are key risks—they will move into care or nursing homes.

In both cases, our responsibility has to be to make sure that that person’s views—that that person’s wishes—are heard loudly and clearly, and everything possible is done to take account of those. In the case of the woman where very little has been done to help her to live in her own home—to adapt it and to provide additional support—we are much more likely to challenge a decision that she needs to move into care than we are with the woman where every effort has been made. That speaks correctly to the code of practice, which makes clear that the responsibility of the IMCA, while it is to make sure that the person has a voice through the process, is to challenge when the decision is not in the person’s best interests. As I say, that takes judgment, takes care, and takes proper training and supervision to do.

So my sense is that the Act is sufficiently clear, and the interpretation of the code of practice is sufficiently clear, but it does mean that organisations need to ensure that people are properly trained and supervised. By and large, I believe that that is what is happening.

**Elyzabeth Hawkes**: It is very difficult. It is a conflict. Take a safeguarding example. You are supporting two different clients. One client wants to make a decision that they still wished to live with this person even though they have spent all their money. Potentially, if you looked at their overall life, if you removed them from that person they would have nobody, they would have no social inclusion and their life as such would be a complete wreck. Just because somebody wants to make an unwise decision does not mean it is a bad one. Take another example where somebody chose to live somewhere where they were continually abused, at risk to life. I think you would have to represent what was best for that person in relation to safeguarding. But I think that is really difficult. The advocates need the support and supervision to be able to take them through that process, because that is quite a call to make.

**Jonathan Senker**: I think there is also a contextual point that it is easier to advance somebody’s wishes knowing that they may be harmful if we have confidence that there is actually somebody out there who is concerned about the harm. The decision-maker is taking their responsibility very seriously, so they can weigh up the fact that somebody may object to something with the harmful impact of that. It is a little bit more difficult to be a strong advocate for something that will be harmful to an individual if there is not that correct pushback and responsibility taken by the decision-maker to weigh up the person’s wishes and views with the other elements of the best-interests checklist.

**Steve Gray**: I think what is central here, of course, is what I think Jonathan and Elyzabeth alluded to earlier: in all instances when somebody lacks capacity, it is about making sure that view is heard, and it is about making sure that that is central to the

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Asist, POhWER, VoiceAbility – Oral Evidence (QQ 106 – 125)

decision-making process. As I see the concept of best interests, we are basically working together, because in one way you will be asking for the person’s views—what they actually want to happen, what their view is of the situation. In the report, that will be clearly stated: “This is what the person wants”. But you also have the freedom to ask questions. At the same time as “This is clearly what the person wants”, using non-instructed advocacy tools, for example, you can ask questions of decision-makers around the areas about the decision that you are making. I agree about also challenging when appropriate. The two things—the person’s view, and the best-interests decisions and questions around them—can be raised by using non-instructed advocacy techniques.

Q113 Lord Faulks: Could I just ask you one more question? It is about the Court of Protection and the various decisions it has been reaching. There is a particular decision called CC v KK. Have you generally found that the decisions of the Court of Protection have been a) sufficiently publicised and obviously accessible to you, and b) helpful at all in performing your role?

Steve Gray: Obviously, we access certain materials and certain information so as to be able to keep up to date with case law, because it is a very important element of the IMCA work. It is a fascinating and rapidly changing area of legislation, and that is what makes the Mental Capacity Act interesting—it is developing all the time, so we have to keep on top of it.

With regard to being helpful, at the moment case law is obviously changing, and that does raise problems in interpretation of the case law. That sometimes affects how decisions are made. An example is the case you are alluding to and DOLS cases where you have different changes in what is seen as deprivation. Different case law suggests something, and you are waiting for other cases to be resolved. That does create problems, because that is not clear. Perhaps not so much for IMCAs but for other people—BIAs, best-interests assessors, for example—it can cause some difficulty, but it is something we have to ensure we keep on top of when working as an IMCA.

Elyzabeth Hawkes: I agree. I think it is accessible for us, if we make the effort to go and make sure that we look for it and include that in our mandatory training. I also think there is benefit to having joint training for best-interests assessors, with DOLS teams and with supervisory bodies, for development in the local area, so that we actually work those examples into best practice and how that will inform our practice in the future. It is there; it is just our responsibility to go and look for it.

Jonathan Senker: That is right. It is at the moment our responsibility to go and look. CC v KK really changes what information may need to be available to people before making a decision. Similarly, case law has developed and changed a lot on the deprivation of liberty safeguards, particularly in the Cheshire West judgment. At the moment, it is up to not just advocacy organisations but other practitioners to go out there and look for the information and, with a piece of legislation that is so fundamental to people’s rights and to people’s lives, there do need to be stronger central channels to actually disseminate practice—not just to advocacy organisations and independent mental capacity advocates, but to social workers, doctors, nurses, lawyers and, in some cases, to bankers and other people. There is a real gap there; there is no single point of authoritative information. There is also a need—Elyzabeth has mentioned the deprivation of liberty safeguards, which is very much now dependent on case law—for
In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.

**Steve Gray**: I agree completely with Jonathan on that point, around DOLS in particular. Things have changed so much in the last few years that new guidance around that would be very useful.

**Q114 Lord Turnberg**: You have spoken a little about training and quality assurance. Do you do your own training, or do people train on a course elsewhere? How do you assure quality?

**Steve Gray**: Basically, we provide training in-house at the moment. We register with City & Guilds and also work through BILD. That is an accredited training provider so it in many ways looks at the quality, because obviously it assesses the work. I guess the main element of our part of the qualification is the provision of the training; it is the training days that we do internally. We provide our own training, and it is assessed and monitored by an external body. We do not do that assessing ourselves.

**Elyzabeth Hawkes**: I would agree. We are affiliated—like a satellite unit—with BILD, with our own internal assessors subject to external verification to make sure that that is all accredited learning. We also add on to that joint training within local authorities or health institutions, particularly for IMCAs, so that they do some of their mental capacity training, safeguarding training and DOLS training with members of DOLS teams supervising who they will work with on a day-to-day basis, so we try to localise that training. If you look, any of our organisations will have a safeguarding policy for how we respond and how we report, but that needs to be meshed in with the local authorities or it is not going to work. It needs to be of a national standard, but it also needs to be locally responsive, so that is why that link locally is important in actual application and practice.

**Jonathan Senker**: We commission our training from other organisations and then build on that in individuals’ personal development plans. I think training is an essential part of delivering a quality service. I think the other part of your question was around quality assurance. We have the quality performance mark, which I know POhWER and Asist also hold, which is an externally evaluated quality mark but one that will need to be reviewed. We also rely very much on our supervisory systems—auditing people’s files; discussing with them how they are working with people; going out and observing people’s work, because it is very much about people’s practice skills as much as people’s ability to describe what their practice skills are; drawing teams together so that they can learn from each other’s experience and share some of the knowledge that we spoke earlier about, the knowledge that is needed in working with people with different specific conditions; as well as the more quantitative evaluation of the work that we do: of outputs, outcomes and so on.

**Lord Turnberg**: Do you turn people down when they apply to work for you?

**Elyzabeth Hawkes**: Yes.

**Steve Gray**: Obviously, people come through a recruitment process, similar to anywhere else. Obviously if they do not meet the line, they are not going to be employed.
Elyzabeth Hawkes: It is also worth adding that anybody we do employ is on a probationary contract, subject to completion and achievement of certain elements of their training before that contract is ever made substantive.

Jonathan Senker: I would just underpin that. We are very conscious of how responsible the role is, and the duty that lies with us to make sure that people are competent to carry out that role. So absolutely—if people are not able to do that well, we do not want to employ them. When we do employ them, we want to do everything reasonable to enhance their ability to do the role effectively, but ultimately we will always decide whether the person can provide a good service to people.

Steve Gray: Internally, we do things like supervision. Supervision is a very important element when you are working with people and service users. Supervision is actually a very good way of checking what is going on out there and how advocates are performing. Also, there are things like database audits. We can look at what people are doing and look at their notes, check those and check what is going on out there. Shadowing is something that you can do. You can go out with advocates, shadow them, follow what they are doing, check out what they are doing. Of course, there is monitoring—getting feedback from decision-makers. We are very keen at the moment on getting feedback from decision-makers after they have been involved with the service. We ask, “What do you think about the service? Was it useful?”. That is an important element for developing the service and seeing whether there are any gaps in quality or whether things are not being provided quite correctly.

Lord Turnberg: So, continuing professional development of people is—

Steve Gray: Essential.

Elyzabeth Hawkes: Building on the feedback point, I also think that there is the opportunity to build feedback, particularly from clients. Even if somebody has used the IMCA service, they can still give feedback on how they found your advocacy support, and we have developed an outcome style that allows people to measure their journey. It has a range of different achievements—social inclusion, feeling safe. It is all to do with social outcomes, and people can still do that. One of the best ways to know you have done a job well is if somebody feels that they are in the right place and they have some control over their lives. That is one of the best outcomes you can get.

Q115 Lord Swinfen: You all do the same work. Do you train each other? Do you learn lessons from each other? Do you have conferences, or are you just working in little boxes?

Jonathan Senker: We actually received some training from Asist and found that incredibly valuable. I believe it is absolutely essential that different organisations work co-operatively, share information and share knowledge. At the moment, we do that rather informally by the links that we develop between organisations. We recognise that there is a very strong need for some umbrella organisation to help draw organisations together. There is a gap at the moment for the advocacy sector, and that is something that we, together with other organisations, are going to need to address in the coming time.

Steve Gray: Traditionally, Action for Advocacy has always provided this service. I believe it is not trading at the moment, but it is looking with its trustees at how it
moves forward. I think we would all agree that Action for Advocacy, as an umbrella organisation, provided a useful mechanism for sharing information nationally. I agree; I think that was very useful.

**Q116 Baroness Andrews:** Just a point of clarification. Coming out of all this, as far as I can see, you are saying that you need to rationalise in some senses, and it is really important that you have national standards rather than a national qualification. Very briefly, how difficult will that be to achieve? Will you have the support of contextual and supporting professions and the people you work with to do that? Is that something which people in this field would want you to do?

**Jonathan Senker:** I think that both are needed. The national training that is available is required. There also needs to be a stronger, updated quality mark for IMCA services. There is one at the moment. It needs to be revised and developed further. That is achievable. The plans for doing that appear to be a little bit unclear at the moment.

**Baroness Andrews:** What does that depend on? If someone is going to clarify that, who is that person or body going to be?

**Jonathan Senker:** The organisation that was responsible for that quality performance mark is no longer in operation. That was Action for Advocacy. I understand that there is some funding that is held by the Department of Health to take forward that work, but that an organisation to do so needs to be identified.

**Steve Gray:** What is key around whatever organisation that is is that that organisation is independent of providers. That would be a very important element.

**Baroness Andrews:** So are you talking about a training organisation here, a commissioning organisation, or a central government department, or—

**Jonathan Senker:** We are talking about an organisation that would develop and administer a quality assessment tool for advocacy organisations, not for the individual advocate. There is a gap there. The other way of approaching this, which also has potential benefit, is to look at professional regulation of individual advocates. There is a very, very strong case for there to be a professional body for individual advocates. It is a key profession providing a very good and important role to generally very high standards. Like other professions that do that, it is right and proper that it is appropriately regulated so that standards are maintained and so that there is some additional assurance for individuals using the service, and their carers and family, about the quality of the individuals with whom they are interacting.

**The Chairman:** I am conscious about the time and the number of questions we still have to cover, so I wonder if I could ask the witnesses to be briefer. There is an opportunity to submit additional information in writing. Can we move on to the next question?

**Q117 Baroness Andrews:** I hope this is quite a brief question. You have said already that you think the code of practice should be updated. You have not said anything about whether you think the Mental Capacity Act itself could be changed in a way that would make your job more effective. We have had evidence saying that there are issues around the definition of serious medical treatment, for example, and I know that, in
terms of the IMCA, it “may”—not “must”—be provided before decisions regarding care reviews. That came in under regulations. Is there anything we could recommend that you would think would make a difference to the way you operated by changing the law?

**Elyzabeth Hawkes**: I think that the Mental Capacity Act usually refer to “should” not “must”, and “may” not “will”. It leaves it open to discretion whether that referral will be made, and I think that could be stronger. I also think that when the Mental Capacity Act refers to safeguarding it says how somebody does not necessarily need to be unbefriended—to not have anybody appropriate to consult. They can still benefit from the input of an IMCA. I do not know how, but I think there is work that can be done with the Mental Capacity Act to direct health and social care professionals more in their statutory duty to make a referral sometimes, perhaps at the point when capacity is about to be assessed. Best practice says that you should perhaps involve the IMCA sooner to give them a better chance: that you should perhaps involve the IMCA around that first point. My personal view is that it would support people to access an IMCA if the Act was more direct about a professional’s duty to consider and to make a referral. If that referral then turns out to be inappropriate, that is okay, because sometimes they are anyway—if somebody regains capacity because they are not dehydrated or they have had antibiotics and they are not infected any more. I think that gives people the best chance to actually use the IMCA to support them.

**Steve Gray**: I think it would be nice to expand on the point about the definition of who is consultable.

**Baroness Andrews**: Who is consultable?

**Steve Gray**: Yes, who is consultable. The Act talks quite usefully about somebody’s interest in the welfare of the person. For some decision-makers, it would be useful if the concept of “Who do we speak to? Who do you talk to? Are these people consultable?” was fleshed out a little more, perhaps in the code of practice, so that it was clear about who was consultable and who was not consultable under the Act.

**Jonathan Senker**: I would agree broadly with the evidence that the Committee has received so far: that it is a good Act that is patchily implemented within local authorities and generally not well implemented within the NHS. There are a good number of things that we think could be done to improve the implementation. How long do we have?

**The Chairman**: Could you submit in writing a list of things that you think could be improved? That would be very useful.

**Jonathan Senker**: Absolutely. Would it be helpful perhaps to mention a couple of them? Certainly there is much too little focus on supported decision-making, enabling people to have a voice and supporting people to make their decisions. Social workers, we find, tend to focus on testing capacity rather than thinking about how to improve capacity and better training and guidance. A colleague of mine talks about people putting on their Mental Capacity Act hat but then forgetting that they should never take it off—that this needs to be a part of the mainstream of the operation.

One of the proposals that I know Members of this Committee supported to amend the Care Bill would see an increasing role for advocacy in assessment, care planning and review as well as in safeguarding. I think those are essential ways of enabling people to
have a voice, rather than waiting for other people to take decisions and for that
decision to be known before that person gets that support. So, for example, the IMCA
role will not be triggered at the moment by somebody who is living a generally unhappy
life in, for example, a care home, unless somebody picks up on that and says, “Actually,
there’s a decision to be made here about whether this person should continue to be
living here”. I do not think that is good enough, and one way of addressing that is by
making sure that there is the involvement of advocacy, assessment, care planning and
review for people who need it most—broadly people whose capacity for decisions that
may arise through that may be comprised.

The Chairman: Could you just submit the rest in writing, because I am conscious that
we are really running out of time. Can we move on to the next question? Lord Patel.

Q118 Lord Patel of Bradford: Mine is around the role of advocacy. Is it different
under the deprivation of liberty safeguards, when you compare it to the role of
advocacy under the Mental Capacity Act provisions? Is the role of advocacy under the
safeguards adequate?

Steve Gray: The role is different. The role between IMCA and IMHA is different. It is
primarily different in the way it is instructed. With IMCA, it is instructed by the
decision-maker when the decision has been made and around that particular decision.
With IMHA, of course, the person is made aware of their rights by the hospital or the
trust, and basically they become the instructing person: they instruct the advocate. That
is one of the main differences between IMHA and IMCA.

Of course, IMHA becomes very much like a more generic role, in many ways. Part of
the responsibility in IMHA is about “These are your rights under the Act”. But it is very
much like a generic advocacy role—about supporting the person through that period of
detention. Also, it tends to be wider in its remit. So, for example, whereas IMCA is very
specific to specific decisions—we have already talked about change of accommodation,
serious medical treatment and so on—IMHA, in my view, is a lot wider. They will deal
with a range of issues involved in that person’s care during the period of the detention.
Those, for me, are some of the main points.

Elyzabeth Hawkes: Could you just repeat the question again for me, please?

Lord Patel of Bradford: Is the role of advocacy under DOLS different from the role
of advocacy under the Mental Capacity Act? Is the role of advocacy adequate enough.

Elyzabeth Hawkes: It is a separate set of skills. It is a different timeframe. There are
statutory requirements. I think it should be—and it is—a specific set of training. It
should not just be added into IMCA—“Oh, it’s just DOLS added on the end”—because
of all the issue types other than serious medical treatment, DOLS referrals are the ones
with the greatest national fluctuations you will see, particularly around 39Ds, when
there is an advocate to support somebody that is being a paid person’s representative. It
should be an individual service. There is a definite set of skills, particularly with
timeframes. For 39As, you only have those five days. You have to do a concise report
that is in time, as the person is not going to have their view represented. So it is
different, and a different set of skills, and it should be an experienced IMCA who has
had the additional DOLS training who provides that service.
Steve Gray: Sorry, my first answer was about IMHA. I thought that was what the original question was.

Lord Patel of Bradford: It was just about DOLS.

Jonathan Senker: Obviously the structures are different. We find the role to be broadly similar in advancing the person’s interests, ensuring that those are taken account of, challenging decisions, and particularly challenging or requesting a review of the deprivations where necessary. I think there is a difference with Section 39D, where our role is to support an unpaid representative. There we have examples of very good practice where we have been able to empower and support relatives and friends to really safeguard the individual and to make sure that decisions are reviewed. We also have frequent examples where the relative or friend does not have the information — support to understand how important the role is. While we attempt to provide that, often they are grateful for the provision of care that is available; they do not want to rock the boat and they do not want further involvement. An important proposal might be that everyone who is subjected to a deprivation of liberty safeguard does have that paid representative who could work effectively alongside family members and friends where necessary, and the level of involvement that may be needed could vary considerably according to the ability of friends and family to carry forward the role. Given that we are talking about depriving people of their liberty—it is such an important move—we need to make sure that there is every safeguard available to people. There is a key gap there.

Steve Gray: In regard to DOLS, one issue for advocates working with DOLS is the time constraints sometimes that actually happen around DOLS. Obviously, we work on a seven-day week here, not a working week. Sometimes the amount of time you have to work with the person is cut down immensely. That can really affect the amount of work input into that decision-making process. Quickly, probably the review process around DOLS could be strengthened in some way to encourage an independent element to the reassessments, very often. If you look at the Mental Health Act and the way the tribunal system works, there is an element of independence in that system. It would be very useful in some way—I do not how it would work—to provide additional safeguards in that situation.

Q119 Baroness Browning: Could I just follow up on Mr Senker’s last contribution? You said that it is essential that we close this gap of a paid IMCA working alongside family and friends when the deprivation of liberties is at stake. Do you think we have closed the Bournewood gap?

Jonathan Senker: I do not think we have done. I do not know whether the decision-making around L, the man at the heart of Bournewood, would be different now than it was when he was detained. I do not have issues particularly with the framework; I think the implementation is very poor or very patchy, and we are seeing increasingly that DOLS acts as something of a sticking plaster for poor community care planning and practice. The kind of conditions that are being agreed are that the person can go out from time to time with support from staff. That should not require us to go through this process; that should be a matter of good community care planning. In one instance, one of the conditions was that the person should have regular social work input rather than a locum social worker where that was very strongly and obviously required. DOLS are acting as a sticking plaster over poor community care planning. The extent of the
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protections they provide is high in areas that engage with it. We know of certain areas where they really discuss these issues. They have provider forums and social work forums that look at the issues and thrash them out in advance. They do well. Areas that do not, do not.

Baroness Browning: It would be nice to have something in writing, if you would not mind, just setting out what you think the problem still is with the so-called Bournewood gap, because we had hoped we had filled it.

Jonathan Senker: Of course. I think it is around implementation.

The Chairman: Baroness Hollins, I think you were going to ask a question that Mr Gray has already answered.

Q120 Baroness Hollins: I think so, although I just wondered: are IMCAs and IMHAs ever the same person? Do people ever do both roles? Is that confusing for them? I suppose one issue is that, of course, sometimes it will be somebody with a learning disability needing an IMHA, and sometimes somebody with a serious mental illness is going to be needing an IMCA. I just wondered whether there was any confusion in practice.

Jonathan Senker: I think it is more confusing when there are two distinct different people than it is when there is one person. I would tend to think that, were I in that situation, I would like to tell my story once rather than twice, and would like to build up some continuity. Whether it is one person or two people depends usually on whether it is one organisation or two organisations. Many commissioners, very sensibly, have drawn together IMCA and IMHA contracts so that they will be let to the same provider, which enables that continuity. That is not always the case.

Lord Swinfen: In your experience, are commissioning plans making sufficient provision for advocacy? Has local commissioning led to an effective market in advocacy services, or are there problems such as supply fragmentation and quality control?

Elyzabeth Hawkes: Commissioning plans are in place. They are sometimes fragmented, because the commissioner for an IMHA service may not be the same commissioning team within the same local authority for an IMCA service. Historically, the money for some parts of advocacy came from different pots. PCT money commissioned IMHA. That is all being pulled together, which I think is a positive effect. Those commissioning plans could be more co-ordinated, so that you do not get fragmentation of services and you do get a whole-person approach. As Jonathan referred to, I might be sectioned under the Mental Health Act and need to have some treatment that is not related to my mental health. Therefore, if I lack capacity, I should technically be entitled to an IMCA. So it is about having that whole-person approach, rather than boxed services.

Jonathan Senker: At the moment, commissioning plans are clearly insufficient for advocacy. IMCA, for example, provides a vital safety net for people who are most vulnerable and facing the biggest decision. But it is reactive: it is only after a decision is identified. It is variable in the implementation of the discretionary elements of it. It is variable in the mandatory elements of it if we look at the referral rates. It only covers certain decisions. It covers where I live. It does not cover who I live with or how I live. We need to make sure there is much more effective support, independent support and
advocacy support; to enhance people’s capacity; and to support people who may have formal capacity but may face enormous hurdles due to the power imbalance that there can be with services, people who cannot get their voices across. Given that there are always going to be finite resources and a finite amount that can be done within commissioning, the key trigger points that people tell us are most important in their lives and the decisions that get made are around assessment, care planning, safeguarding and review. Much stronger commissioning plans are needed to address those areas.

**Steve Gray**: I think what Jonathan alluded to there was that there is a massive area in which people need support outside IMCA. Bearing in mind that we are talking about advocacy services, there are wider issues here, part of which are commissioning general, generic services. A lot of people do not fit the IMCA remit, so I think it is about making commissioners aware of that, and the importance of that in ensuring that people have their voice heard within what are some very challenging times.

**Q121 Baroness Shephard of Northwold**: The report produced by the Department of Health on the first five years of IMCA does reveal extraordinarily huge variation in the rates of IMCA referral across different authorities. I really would like to hear your views on the reasons for this. I think, Ms Hawkes, you work in the east of England.

**Elyzabeth Hawkes**: Central and east.

**Baroness Shephard of Northwold**: Central and east. Bedfordshire appears to be either singularly without problems or singularly in difficulty in solving them—one or the other. I wonder if we could have some of your views on the variation rate.

**Jonathan Senker**: It is extremely concerning, because we are talking about a variation in whether people’s legal entitlement is met. We have found that it depends so much on local leadership. Where there are effective Mental Capacity Act leads, preferably supported by senior managers within local authorities, they raise awareness, discuss the issues within provider forums, discuss the issues within professional groups with social workers, and ensure that there is effective training within the NHS. The variance in referrals around serious medical treatment is also deeply, deeply concerning. We have found that it depends very much on local leadership.

We think that a lot more is needed in order to make it matter to senior managers within local authorities and within the NHS. It needs to be properly monitored. Training needs to be provided—so, for example, looking at the NHS, were the CQC to be holding NHS providers’ toes to the fire in the amount of mandatory training that is being provided on the Mental Capacity Act to clinicians and so on, I think we would start to see some improvements. At the moment we see good local authorities that get it—that encourage referrals and build it into their systems—and some good NHS providers that do that, again by integrating it within their working groups and within their referral forms and systems. But there do not seem to be strong incentives to ensure that that happens more generally.

**Baroness Shephard of Northwold**: Can I ask you therefore: from whom should the local leadership come? Secondly, who ought to be stimulating the existence of the local leadership?
Jonathan Senker: I think it does need to be coming from a senior level—from directors of adult social services—because it is very much about the culture of how authorities work. I think it is about ensuring that there is an effective Mental Capacity Act lead and providing good support and resources to them. Within the NHS, it is from the chief executive downwards.

Baroness Shepheard of Northwold: If there are whole bits of local authorities and local health services that appear to be performing, shall we say, less frequently than others—I make no other judgment—would that be a matter for the CQC or for the Department of Health? Who would be keeping an eye out for these statistics?

Jonathan Senker: I think these are really key questions, and I am not sure that I have the answer. Certainly, I think that the CQC should be inspecting hospitals and explicitly drawing attention to issues around training and referral rates in the Mental Capacity Act. I know that when they inspect care homes, they look at the training that staff have, but I think there is a variance in how searching their questioning is around that. Certainly, the CQC can perform an important role in this.

Baroness Shepheard of Northwold: But who would be performing that role with local authorities?

Jonathan Senker: I am not certain of the answer to that one.

Baroness Shepheard of Northwold: Okay. Thank you. That is fine.

Elyzabeth Hawkes: I think, from my point of view, there is a definite role for us as advocacy providers to make sure that we fulfil our duties to make the service accessible and available, but I also think that there are limits as to how we can do that. If you take serious medical treatment as an example and you think of that within an acute care setting, you potentially have the doctors who would be the people who would do that. They would perhaps be house officers, middle grades on that rotation. You have a moving body of staff who you continually have to educate, plus—with the greatest respect—a group of consultants who do not necessarily see any responsibility under the Mental Capacity Act as the first thing on their agenda. They learn about informed consent, but how does the Mental Capacity Act and their responsibilities under that lead into that informed consent? How can you say that you have taken consent if you do not have that set of rules in your head? That is where I think, fundamentally—again, I am not sure of the answer—there needs to be a more robust way, whether it is training, whether it is reaccreditation, whether it is CME, of making sure that that knowledge is there and is put into practice. That is in relation to all staff who have that responsibility. That would be my view on serious medical treatment.

On the other issue, around low referrals and how we act on that, sometimes the commissioning monitoring is done by commissioners who do not necessarily have a clinical or an operational input into that. I think there is a need for greater partnership working between commissioners of services and deliverers of services in that monitoring of performance of contracts, with our input, in terms of our activity.

Q122 Baroness Shepheard of Northwold: Can I just ask you—actually, it would be a question to any of you—in the light of the statistics in this report, in the roles that you

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fulfil have you been aware of any activity that would indicate that someone else was worried about the disparity? In other words—well, you know what I mean.

_Elyzabeth Hawkes:_ Yes. Are you referring to the disparity between the detail on the DoH database and our inputting into that?

_Baroness Shephard of Northwold:_ I am worried about the disparity revealed by the statistics in this report, which is where I got the statistic about Bedfordshire. Maybe that is how things are there, but you are concerned about this disparity. We are. All I am asking is: when this information became available, were you aware of any particular leadership being exercised nationally by the Department of Health, or anything saying, “Look here, this won’t do”?  

_Elyzabeth Hawkes:_ No.

_Jonathan Senker:_ I am afraid not, no.

_Q123  Lord Turnberg:_ Two brief questions. Supposing everyone out there suddenly realises the value of your service and comes out of the woodwork, do you have the capacity to respond? Do you have enough people or enough money? The other brief question, and maybe you do not want to answer this, is: do you know whether the CCGs—the clinical commissioning groups—have any of this on their agendas?

_Steve Gray:_ With regard to the numbers, resources are finite, I guess. If we suddenly had loads of referrals it would be a problem. Funding has been cut for our IMCA contract over the period. I guess, yes, if we suddenly had loads of referrals it would be an issue. If at that stage it became an issue, we would have to go back to our commissioners and say, “This is now an issue”. Sorry, what was your second question?

_Lord Turnberg:_ I asked about CCGs.

_Steve Gray:_ It is interesting, because for general advocacy CCGs are an issue for us. Our area has six CCGs at the moment, and before it was one contract. At the moment we are in negotiation with a lot of different CCGs, which is quite difficult. They are aware of generic services. In our county they do not commission the IMCA service; that is done by the local authority. I cannot answer the question about whether they are aware of it but fragmentation can be difficult for advocacy generally—for making the right contacts and making sure that things are on the agenda.

_Elyzabeth Hawkes:_ We have done a lot of work with CCGs recently around some of the health complaints advocacy that has come into local funding. That has given us the opportunity to talk about other forms of advocacy. There is, in my opinion, a lack of knowledge about the value of advocacy and the statutory duty for some of the services to refer. For example, very briefly, I went to see a CCG about what IMCA services were and had to give impromptu training on the Mental Capacity Act. You cannot do one without the other knowledge being there first, and it is not there.

_The Chairman:_ Lord Alderdice, I think to some extent this question has been answered, but maybe you want to ask it.

_Q124  Lord Alderdice:_ I just want to press a little, because I think you said that there is not currently a national professional body or national standards. You indicated an
interest in some kind of statutory regulation. There are usually two ways in which a national professional body develops. One is that all the people in the area get together for a national conference and put something together on paper which they gradually develop over a year or two. The second is that there is a current national professional body, of a more generic kind, that sets up some kind of sub-group that says, “Okay, we will act as your professional body and you will be a specialist group within that”. Have you any particular views on whether it is likely that either of these will be adopted? It sounded as though you thought it would be a good idea to have some kind of national professional body; how do you see it coming into existence?

*Jonathan Senker:* I would imagine that the logical choice would probably be the Health and Care Professions Council. It exists and regulates other professions. That would probably provide a relatively quick route to achieving this.

*Lord Alderdice:* But it accepts professional organisations that exist. It does not set them up itself, so you would have to set up a professional organisation and then seek to be regulated by it.

*Steve Gray:* One of the other issues around this is the concept of a protected title. If you start looking at professional bodies and whether you have a professional advocate or some kind of protected title—

*Lord Alderdice:* That is a subsequent issue of statutory regulation. Usually, for example in something such as psychotherapy or counselling, you first have a professional body and then seek regulation, registration and so on. It sounds as though you are quite a way back in the process.

*Elyzabeth Hawkes:* I think we are a long way back. Recently, I think audiologists and some of the complementary therapies wanted to be accepted as professions that can be regulated and registered. That is a challenge if you enter into another organisation. I think it is something that advocacy providers nationally need to decide, in partnership, how they wish to take that forward. I do not think it is something that we can do as individuals.

*Steve Gray:* But clearly, if you develop a body and you move along to talk about protected titles, registration and so on, that would of course incur a cost for organisations. That would potentially be an issue for smaller organisations. Also, if you are talking about protecting the role of a protected title, will we want to say that only certain people can advocate? That would potentially prevent smaller grass-roots organisations coming into being because they could not advocate. When you think about where advocacy came from, it was the grass roots and communities coming together to raise issues. That is something that you have to consider: who would this exclude and what costs would be incurred by organisations? In the end, it should not just be big organisations that are able to survive in that kind of marketplace.

*The Chairman:* I think the last question to be asked is whether you have anything further to add and about changes to legislation or implementation. Could I ask you to submit the answer to that in writing, as you will for the changes anyway? I have been asked by Baroness Andrews, who had to leave, to raise one matter. She picked up that one of you mentioned that it was no longer part of your role to promote the existence
of your services. If she has picked that up correctly, has this had an impact on referrals? What happened to change that role?

Jonathan Senker: I do not think she heard that entirely correctly. I think the point we made as a panel was that our commissioning arrangements have become increasingly restrictive and focused on just paying for the work that is done with individuals and work on their behalf, which tends to give lower priority to encouraging referrals and raising awareness. Each of our organisations is still very determined to do that work but we feel that it is under increasing pressure as that role is not sufficiently built into contracts and pricing. We are very conscious of our informal positions as ambassadors not just for our own services and the independent Mental Capacity Act Advocacy Service, but for the Mental Capacity Act and its ways of working. We do our best to maintain that, but it is coming under increasing pressure. At the extreme, we are seeing spot-purchasing contracts, which will pay only when someone has already been referred and, in one case, a Dutch auction where providers were encouraged, on a live event, to produce a lower and lower price. Those things can mean that that wider role gets squeezed out. What we hear generally is that we have a good Act poorly implemented. We cannot afford to lose any of the resources that help to implement it more effectively. It is that risk that we have been talking about.

Q125 Baroness Browning: We have recently received the report from Baroness Neuberger on the Liverpool care pathway, which makes reference to the role of IMCAs. There will be changes, thank goodness, but, until now, have you and the people you work with been conscious of the fact that, in end-of-life matters, the NHS and care homes—NHS hospitals particularly—have not called on IMCAs when they should?

Jonathan Senker: Yes, very much so. We have been involved with people quite frequently and become aware, incidentally, that they are on a “do not attempt to resuscitate” order. We have called people to account on that and in almost all cases made sure that the “do not attempt to resuscitate” order was either rescinded or that it was there as the result of a proper process of involvement and consultation. However, we have found that it is a recurrent problem in a number of different hospitals, and we are very interested in exploring with NHS England how we generalise some of the learning, particularly around “do not attempt to resuscitate” orders, which may or may not be addressed by the changes to the Liverpool care pathway. I suspect it will not of itself be addressed, so that is a “yes”, unfortunately: it is something that we come across quite regularly and frequently.

Baroness Browning: Thank you. As a result of that report, every case in hospital at the moment is, we are told, being looked at, but there will be a six-month gap while the new procedures that will follow are worked out. With regard to your service and end-of-life matters, if you have not already done so, could you make this Committee aware, through the Chairman, of what you think should be done, the correct procedures that should be followed and the role of IMCAs in end-of-life matters?

Jonathan Senker: Yes, we would be happy to submit evidence on that.

The Chairman: Thank you very much for your time this morning; it has been very enlightening. Apart from the information that you have indicated you will submit to the Committee Clerk, could I encourage you, if you have not already done so, to give serious consideration to submitting written evidence?

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Jonathan Senker: Thank you very much.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Asist – Written evidence

Thank you for the opportunity to provide oral evidence to the Select Committee on the Mental Capacity Act. Set out below are some additional issues we would like to raise as part of this inquiry.

1. "Is the act widely known and understood by professions required to implement it? How does this differ across the different sectors, such as health, social care banking and others?"

In our experience the knowledge and practical application of the Mental Capacity Act continues to be variable across the health and social care sector. We are particularly concerned about the low number of serious mental treatment decision referrals made to the IMCA service from Trusts and GP’s.

The lack of sanctions for decision makers who fail to comply fully with the act in our view reduces the safeguards that the act intended.

2. "Has the level of referrals to IMCA met expectations? What are the reasons for the regional variations on the number of referrals?"

As mentioned above there continues to low number of referrals form some professionals particularly from hospital trust and General Practitioners. A reduction in funding streams for IMCA services in the past couple of years as resulted in a reduction in the amount of awareness sessions IMCA services are able to provide to health and social care professionals.

3. "Are the safeguard in the Deprivation of Liberty adequate?"

The identification of a deprivation of liberty is largely depended on the managing authority affectively identifying and responding appropriately to a possible deprivation. Clearly if managing authorities do not undertake their responsibilities appropriately this limits protection afforded by the safeguards. In addition the complexity of the depravation of liberty safeguards documentation makes the process onerous for all involved.

Whilst the current safeguards offer the opportunity for RPR’s or IMCA’s to requests reviews, one may observe that there is currently a lack of independence in the review process. When considering the review process one could compare the safeguards offered the deprivation process with the greater protection in our view afforded by the Mental Health Act e.g. access to independent tribunal service, managers hearings, automatic tribunals and access to free legal advice.

Given that the majority of Deprivation of Liberty Assessments have to be completed within seven calendar days; the amount of input an IMCA can provide can on occasions be lacking due to these imposed time constraints.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Asist – Written evidence

4. "Are those directly affected by the Act being enabled and supported to make decision for themselves for a greater or lesser extent than they would have been in the past…?"

Decision makers in our view could in some situations make more robust attempts to ensure that people are supported to actively make decisions for themselves before resorting to making a best interest decision. Decision makers should also be encouraged to refer to generic advocacy services for support during these processes.

Thank you again for allowing us to input to this process.

Steve Gray
Director of Operations

1 September 2013

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Association of Directors of Adult Social Services (ADASS) – Written evidence

ADASS

The Association of Directors of Adult Social Services (ADASS) represents Directors of Adult Social Services in Local Authorities in England. As well as having statutory responsibilities for the commissioning and provision of social care, ADASS members often also share a number of responsibilities for the commissioning and provision of housing, leisure, library, culture, arts, community services and increasingly, Children’s Social Care within their Councils.

Comments

Please note, these comments below are also supplemented by the response prepared by the ADASS West Midlands Region, Deprivation of Liberty Safeguards (DoLS) group, to which the ADASS Mental Health Policy Network endorses. The ADASS West Midlands Region DoLS submission is attached (Appendix 1).

ADASS Comments in addition to ADASS West Midlands Region DoLS submission:

Consistency and focus upon benefit and outcomes for service users

1. ADASS notes concerns at the fact there are differences across the country in the way the Mental Capacity Act 2005 has been implemented.

2. However ADASS is of the view that the sector is now moving towards a clearer understanding of what constitutes good practice in terms of improved outcomes for service users and their carers, and welcomes the recent SCIE guidance (http://www.scie.org.uk/publications/reports/report66.pdf) and the first peer review of the MCA and DOLS to be held in November which is looking to review safeguarding standards (Appendix 2).

Court Cases

3. ADASS notes that a number of Directors of Adult Social Services have expressed concerns about the rising rate of legislation around this Act, with an increasing role for 'no win no fee' solicitors seeking compensation, (For example East Cheshire is facing a court case at the Supreme Court this month )

4. Whilst ADASS welcomes increased guidance on what constitutes good practice, it is important that the approach is consistent and transparent (as detailed in strengthen Primary Legislation) rather than determined by case

Guardianship

5. ADASS welcomes further consideration of the option of “Guardianship “in terms of protecting vulnerable individuals”, although ADASS does not advocate changes to the
Act but rather to be addressed through development of consistent standards to be applied across the sector.

**SUMMARY**
The 14 local Authorities in the West Midlands submit the following views.

The consensus is that in the main MCA has achieved its aims in part. Successful implementation has varied dependent on the priority it has been given. The key element in successful implementation has been the continued provision of the MCA grant and where local authorities have managed to maintain a specialist role, implementation has been successful.

A specific power for the purpose of conveying a person following a best interest’s decision to remove someone to a care home or hospital may make this area clearer for practitioners.

The principles underpinning the Act are clear and if followed, ensure compliant practice. They provide a value base on which training and development can be based.

All Local Authorities completed a best practice tool in 2007; this was a highly effective in assessing readiness for initial implementation. Follow up to this could easily be developed nationally. Local audits have taken place. Links with Safeguarding Boards are essential for ongoing monitoring of implementation.

The initial provision of Regional and National Leads gave a coherent message and direction was given. It has been assessed by the group that this support was withdrawn too soon into implementation. This has allowed for there to be no central direction on interpretation of case law.

A further concern has been that grant funding has continued but this has not been ring fenced. Given the current budgetary constraints in the Local Authority this can in some cases dilute the funds being used for MCA.

Professionals working in health and social care are aware of the Act and it has formed an integral part of the assessment process proportionate to the amount of training delivered.

One of the difficulties in practice is identification of decision maker. For example when the decision maker is family or informal carers they may not have the knowledge or expertise of the application of the Act needed to make compliant decisions. Such disputes are then more likely to be placed before the Court now to ensure the rights of the carer are equally heard.

The Act has brought about a move away from paternalism towards empowerment and rights based provision in the person’s best interests. Capacity is no longer seen as the remit of “experts”.

People are being better supported to make decisions but generic staff need specialist training. Service users who are self-funding need support with assessing capacity and making best interests decisions. The MCA, if correctly applied, strikes the perfect balance between families’ rights and responsibilities. The involvement of an IMCA

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
ensures voice for service users. Their role has developed into a highly specialised resource.

Serious Medical Treatment referrals are low and this may relate to the difficulty engaging hospital Consultants with training.

The DoLS are rights based and capacity-focussed response to an identified gap in the UK Law. They are effective in subjecting cases of suspected deprivation to scrutiny and assessment. People are going home from care homes that may otherwise have been forgotten. However the time limit for Urgent authorisations is too short and does not always allow for a comprehensive review of a case as the time limits are so short. A way of resolving this issue would be to allow for one application with a longer (perhaps 14-day) response time. The process could be simplified.

The overlap between MHA and MCA in general is misunderstood. Joint training is needed between BIA’s, AMHP’s and DoLS MHA’s to ensure learning takes place from each perspective.

DoLS authorises a deprivation of liberty on the basis of best interests. This is not incompatible with the United Nations Convention on the Rights of Persons with Disability.

### Evidence for

HOUSE OF LORDS
Select Committee on the Mental Capacity Act 2005
West Midlands Regional DoLS Leads Group

### Overview and context

1. **To what extent has the Mental Capacity Act 2005 (MCA) achieved its aims?**

   - The framework has produced a change in thinking that is now centred on the needs of the individual and their individual circumstances.

   - The framework has increased worker confidence when dealing with other professionals.

   - It confirms good practice – therefore enabling worker to go through the process with increased confidence.

   - Helps with supporting risky decision making and has meant that this is seen in a more positive light.

   - More formal and focused Assessment.

   - There is a clearer structure for Best Interest Assessments this helps to clarify the process.
Hospital and Health staff have adopted the principles of MCA to a lesser degree, as the medical condition/diagnosis seems to take precedence over mental capacity act concerns.

MCA needs to be more embedded into Health Professional Training.

The large complex MCA decisions are generally thought to be well made but the small every day decisions – which are often the most important to the Client can be less clear.

Successful implementation has varied dependent on the priority it has been given in the organisation.

Every aspect of the core business of health and care professionals is impacted by the Act.

Local Authorities and other bodies have had to accept that they cannot make decisions for people where they have capacity, even if this involves them in risky decisions. This core culture change will continue to take time to embed.

The changes in documentation, assessment content, policies and procedures needed to ensure that people are empowered to make decisions, take time to put in place.

The key element in successful implementation has been the continued provision of the MCA grant and where local authorities have managed to maintain a specialist role, implementation has been successful. However, with grant funding no longer ring fenced which could give rise to concern about the future specialist roles for MCA.

Training across the health and care workforce, the independent sector and families and carers has been instrumental in disseminating the messages of the MCA.

Having a dedicated MCA lead helps successful implementation and ensures consistency. Case law needs to be shared and the effects must be incorporated into practice.

The West Midlands Regional DoLS Leads Group has carried out extensive work to review the original DoH DoLS Forms. This was primarily to ensure the voice of the relevant person was clearly heard and represented in the process. Best Interests Assessors were often consulting, as required by s4 of the Act, but were not recording the views of P or of relatives and others. This has been addressed by adding specific sections to the Forms.

2. Which areas of the Act, if any, require amendment, and how?

Amendments to the substantive Act may be required in terms of Conveyance. There is still confusion as to where the MCA and the DoLS diverge. A specific power to convey following a best interests decision to remove someone to a
In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.

- Issues of particular difficulty are removal from home and restraint necessary to provide essential care.

- Greater clarity could be provided in the Code of Practice addressing the more complex areas which social care and health professionals encounter, rather than the very simplistic examples which are given.

- The West Midlands Regional DoLS Leads Group (WMRDLG) is developing a regional conveyance policy under the MCA. It is also developing a regional document on restraint, restriction and removal from home. This is to ensure regional application of the MCA principles with consistency and to give a clear lead and direction across the region in relation to definitions and application in practice.

3. **At the core of the MCA are its principles and definitions of capacity and best interests. Are these appropriate?**

- The principles underpinning the Act are clear and if followed, ensure compliant practice.

- They provide a value base on which training and development can be based. The definition of capacity is clear although the diagnostic test is open to interpretation. There is no indication of the need for any degree of impairment as this is tested by the functional approach which comes next. There is sometimes a tension with the assessment of mental disorder and the diagnostic test for general capacity decisions.

- The concept of best interests is still developing. Its progression from being almost an entirely medical concept, to a holistic concept encompassing well-being and emotional and psychological health, is an extremely positive effect of the MCA.

- The Court of Protection are leading the way in directing professionals away from the “protection imperative” and towards rights based responses which incorporate positive risk taking. This is a highly successful outcome of the Act. This is particularly powerful in the work of BIA’s who are becoming a highly skilled set of professionals. Their ability to step outside generic practice and focus on best interests is producing excellent work and challenging risk adverse practice.

- The WMRDLG have developed a new Form 10 for BIA’s which assists with best interest’s decision making for DoLS. This form is based on a best practice document also developed by the group and shared with all BIA’s in the region. The group also developed guidelines for practitioners and DoLS Authorisers to support more robust and consistent decision making and they are just about to begin an audit of practice with a specifically designed audit tool.

**Implementation**

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
1. **To what extent have the five principles of the MCA been implemented in frontline practice? What evidence is available to assess this? Is there a satisfactory balance between enablement and protection?**

- All Local Authorities initially completed a best practice tool developed by the DH in 2007; this was a highly effective tool in assessing readiness for initial implementation. Follow up to this could easily be developed nationally.

- Local audits have taken place and the West Midlands plan a regional DoLS Audit tool.

- Some Local Implementation Groups still meet and where they do this provides a valuable resource. Where these groups link to Safeguarding Boards this provides ongoing monitoring and scrutiny.

- Joint working is key to successful implementation and the delivery of a coherent and consistent message.

- Recognition of unwise decisions is accepted but family carers find this issue difficult.

- There has been discussions in some areas about dealing with the balance of enablement and protection via the use of multi agency professionals meeting. This enables agencies to ensure that risk is managed collectively and reviewed regularly. I.e. in the case of self neglect/fluctuating capacity.

2. **How effective was the Government’s implementation plan? What measures were taken to ensure that professionals and families of those who lack capacity know about and act in accordance with the provisions of the MCA? Has it led to sustainable change?**

- The initial implementation plan was effective. By providing Regional and National Leads to support the work a coherent message and direction was established. This support was withdrawn too soon into implementation.

- Grant funding has continued but is not ring fenced and is not transparent therefore easily transferred to other areas of spending. There is no central direction on interpretation of case law as there was in the beginning and no centralised circulation method or methodology for dissemination of information.

- The West Midlands Regional DoLS Leads group has risen from the ashes to become a highly functioning group providing leadership and direction across the region in improving practice, developing tools and raising standards.

- The work with families is still ongoing and an area of much needed investment. Publications, films, support and advice are still needed to ensure that families are aware of the rights of the person they care for. The implications of the Act for 16 and 17 year olds is a specialist area in its own right and the parents of young people need targeted material to support them, and the young people need specific programmes to inform them of their rights under the Act.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
3. Is the Act widely known and understood by professionals required to implement it? How does this differ across different sectors, such as health, social care, banking and others?

- Professionals working in health and social care are aware of the Act and it has formed an integral part of the assessment process. This can be dependent on the amount of training delivered and whether this training is organic and grows in response to new issues.

- From the experience of the group: training provision for the harder to reach groups such as the medical Consultants working in hospitals. This group does not have an easily identifiable corporate identity and it has been hard to persuade them of the relevance of MCA for everyone, not just for those working in Mental Health.

- Some of the West Midlands Regional Group found that decision making in hospitals often seems to be age discriminatory and very risk averse with decisions made by statements rather than by assessment as directed under the Act.

- Legislation generally is not as ingrained in Adults Services as it is in Children’s Services.

- The need for reinforcement and the 5 core principles to be widely accessible to staff when in that decision making process. i.e. Posters on walls as reminders.

- MCA does not seem to have reached as far as Schools yet.

- Police appear to work on the initial assumption that a person has capacity.

- Health’s initial main focus tends to be diagnosis first.

4. Is the Act widely known and understood by those who are directly affected by it and by their non-professional carers? To what extent does the Act provide protection and reassurance for informal carers? Has the right balance between protection of the carer and protection of the individual lacking capacity?

- One of the difficulties in application of the Act is identification of decision maker. There are times when this is family or informal carers but they do not usually have the knowledge or expertise of the application of the Act needed to make compliant decisions. Practitioners need to be alert to this and willing to support people.

- There are many self-funding service users who require help and support due to issues of mental capacity and therefore need allocation to a social worker. The role of IMCA only supports those who do not have family or friends when often it is the family and friends who need support to understand and apply the principles of the Act.

- Disputes are more likely to be placed before the Court now to ensure the rights of the carer are equally heard.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
• MCA is not as widely known or understood by carers/family.

• Carers often struggle with the decisions made in accordance with the Act and think them unwise. Least restrictive decisions are sometimes viewed as being wrong by the carer. Sometimes parents/family sees the decision made as a threat to the person’s well being. This can cause conflict with family/carer – unsafe sexual relationships are an example of this.

• Media – no support for MCA and this is reinforced in society as a whole.

5. Has the Act ushered in the expected, or any, change in the culture of care?

• The Act has brought about changes in the culture of care. A move away from paternalism towards empowerment and rights based provision in the person’s best interests. The Act ensures Human Rights issues are appropriately considered in the assessment and care management process.

• Staff working at all levels expect to consider capacity in their day to day work. It is no longer seen as the remit of “experts” or of mental health professionals. However it is essential that the principles are correctly embedded and supported by rigorous training programmes as it is easy for direct care providers, for example, to pick up the language of best interests without acquiring the understanding of its full meaning.

• The balance is always between rights and risks, and the MCA helps to ensure this is correctly applied.

6. Is there any evidence that the provisions of the MCA affect some groups disproportionately? If so, what data exists to compare representation across different socio-economic groups, Black and Minority Ethnic groups, and gender?

• The only data which is mandatory relates to the DoLS and this does not suggest that the provisions are experienced any differently by any particular group.

Decision making

1. Are those directly affected by the Act being enabled and supported to make decisions for themselves to a greater or lesser extent than they would have been in the past? Does the means by which the decision is made – ‘general authority’, Lasting Power of Attorney, deputyship, Court of Protection – affect the quality of decision making?

• People are being supported to make decisions more than previously but this is an area which can be developed further. Generic staff will not have had training in communication. The Act has made this a priority and specialist training is needed - communicating with the person with dementia, communicating with severely autistic people, for example, are specialist areas.
• Service users who are self-funding still need support with assessing capacity and making best interests decisions. Even if family members hold an LPA, they are rarely aware of the requirements of the Act and need the support and guidance of social workers. This has resulted in increased workloads for social workers.

• The need to apply to the Court of Protection for resolution in areas of dispute or complexity has provided welcome scrutiny for local authority decision making. Although the process is lengthy and time consuming, the decisions are helpful and often influence the policy development for others. Sadly, the cases which attract publicity from the Court of Protection are often those where Local Authorities have failed in their duties under the Act, or failed to correctly apply the principles. There are numerous other examples of good decision making where applications have been made to the Court in a timely manner and the Act has been correctly applied to empower the service user.

2. Has the MCA fostered appropriate involvement of carers and families in decision-making?

• The MCA, if correctly applied, strikes the perfect balance between families’ rights and responsibilities, and clarifies who is the decision maker and when this is or is not the family member. The IMCA role would be beneficial if it also related to situations of dispute rather than simply where there are no family or friends to consult with.

• Best interests meetings ensure that families and carers are fully involved in the process of decision making. Even where families offer a dissenting or oppositional view their views are recorded and considered by the decision maker. It can often be the case that the vehicle of a best interests meeting is the means by which family understand the implications of the MCA for the first time.

• Family consultation is at the heart of the DoLS process often during a very difficult time for them.

• The role of the BIA as a conduit to other professionals is becoming extremely valuable. The family member is able to give their views and opinions on best interests and to see these views recorded thoroughly in the final report.

• The role of the BIA in clearly explaining to family members the meaning of DoLS cannot be underestimated. People can be very frightened by the language and need to understand this as something to protect their loved one rather than something punitive.

• Family members are often selected as the Relevant Persons Representative under DoLS and can have additional support with this role from an IMCA. It is rare for family not to be selected if they wish to take on this role.

3. Has the role of the Independent Mental Capacity Advocate (IMCA) succeeded in providing a voice for clients and an additional safeguard against abuse and exploitation for those who have no-one to speak on their behalf?

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
The involvement of an IMCA is generally very valuable in ensuring a voice for service users. Their role has developed into a highly specialised resource. There is perhaps a need for more enforcement in terms of the Report they produce to Decision makers.

Most Local Authorities have good liaison with their IMCA providers.

4. Has the level of referrals to IMCAs met expectations? What are the reasons for the regional variations in the number of referrals?

In general there is a still a way to go in terms of IMCA referrals. Serious Medical Treatment referrals are low and it would seem that this may directly relate to the difficulty engaging hospital Consultants with training programmes.

Some Authorities in the West Midlands have above average amount of referrals to IMCAs when taking into account other similar size local authorities. Possibly this is because it is a local resources and not a national one.

DoLS referrals are made directly from the DoLS team and are likely to be accurate.

Regional variations probably depend on the existence of a clear expert or MCA lead, the amount of training provision and the existence of local Implementation groups for scrutiny as well as demographic circumstances.

IMCAs themselves are a specialist source of non-instructed advocacy and useful in situations outside the generally commissioned service.

Deprivation of Liberty Safeguards

1. Are the safeguards in the Deprivation of Liberty Safeguards (DoLS) adequate?

The DoLS Safeguards attract a lot of criticism nationally. Often from those in the Mental Health field who may not actually administer them or apply them. There is minimal if any research into the impact of the safeguards on people subject to them.

The safeguards are a new, rights based, capacity-focussed response to an identified gap in the UK Law. The DoLS are effective in subjecting cases of suspected deprivation to scrutiny and assessment. The DoLS are challenging.

The ongoing development of definition and interpretation of meaning is challenging but people are protected now who have never been protected before, such as those with a learning disability who do not fit the definition within the MHA. The process ensures this protection is provided to them and is scrutinised fully.

The dissemination of information and meaning requires ongoing communication and training for Managing Authorities, and centralised support and leadership.
was withdrawn too soon. Managing Authorities lack confidence in identifying restrictions and supervisory bodies need to respond to this.

- The concept of BIAs as a distinctly different role to AMHPs is extremely valuable. A new type of professional is emerging skilled in putting the person first, challenging assumptions, challenging risk averse practice and clearly identifying the least restrictive option. People are going home from care homes that may otherwise have been forgotten.

- As an independent professional, the BIA is able to challenge over-protective practice within Local Authorities. MCA principles are adhered to in establishing the building blocks to support placements and challenge inadequate risk assessments.

- Clinical decision making which often is made on the basis of age alone can be challenged and changes are made which promote the persons autonomy.

- Part of the process also ensures scrutiny of care planning within care homes and many changes have occurred for the person resulting in improvements to their care even though they may be deprived of liberty, as a result of the involvement of a BIA.

- The WMRDLG have carried out extensive work to provide leadership and direction in relation to DoLS practice across the region. The groups’ focus is on benchmarking aimed at raising quality and consistency of practice.

- The opponents of DoLS appear to focus on the interaction with the Mental Health Act and the ways in which Guardianship could have been used instead. It must be remembered that this option was explored initially and rejected by the Government. The DoLS focus is on the person, their wishes and feelings and their perception of the situation and it encompasses the whole of the MCA principles. The assessment is complex but holistic and consultation is a key element.

- Hospital DoLS ensure safe delivery of treatment for people usually during particularly difficult circumstances. DoLS in care homes are usually a longer term safeguard.

- There are undoubtedly bureaucratic changes which would improve the smooth running of DoLS, some are mentioned in the response to the next question. There are some circumstances which have not been envisaged, such as suspension of an authorisation for any reason other than failing eligibility – for example the person could be admitted to an acute hospital from a care home and there is no facility to suspend the authorisation; the person could go on holiday and there is no facility to suspend the authorisation.

- Repeat requests for authorisations require less detail to be given and some reviews are very specific and do not have associated Forms. The WMRDLG has adopted Forms to address this regionally. One is a repeat request form and another is a hospital discharge review.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
• The ability to set conditions is a useful tool but there is no provision for enforcement. This would be a useful addition.

2. Are the processes for authorisation, review and challenge of DoLS sufficiently clear, accessible and timely?

• The process is without a doubt convoluted but it is also effective.

• The time limit for Urgent authorisations is too short and can be a barrier to providing a detailed overview of a case. The Government envisaged that Urgent authorisations would be for “sudden unforeseen circumstances” however, in practice, a majority of first time applications are Urgent. This is because a deprivation is much easier to identify if the person is in situ rather than assessing a hypothetical care plan and a hypothetical set of restrictions.

• The above could be addressed via creating one application with a longer, perhaps 14-day, response time. The Managing Authority could simply state the date from which it is required.

• Although the process is administratively difficult from the Supervisory Body perspective, it is straightforward from a Managing Authority perspective (although they dislike the complexity of the forms). They are simply required to identify when restrictions exceed those allowed by the MCA and then request a DoLS authorisation.

• The training needs result from the requirement that they identify, as far as possible, when a restriction has exceeded what is allowed under the MCA. This requires training for all staff in the MCA itself, in the DoLS and, particularly, the ever changing concept of deprivation of liberty.

• Reviews are easily accessible.

• The process of application to the Court of Protection is a huge jump from a basic decision to a High Court scrutiny. People who are supported by Paid Representatives are likely to be aware of their rights to challenge decisions. People with family members as representatives may not always be advised of their right to challenge decisions. This is because there is an inherent tension in the role. Often there is a tension between the views of the family member and those of relevant person. The relevant person may desire to leave a care home whilst the family member may wish them to remain there.

• It would perhaps be better if all people deprived of their liberty had a paid representative ensuring parity of information and access to appeal.

• It would be more timely if local tribunals heard a first tier level of appeal with the right of further challenge to the Court of Appeal.

Other legislation

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
1. **How well is the relationship with the mental health system and legislation understood in practice?**

   - This is an area which grows in complexity as the Act is implemented in practice. The overlap between MHA and MCA in general is misunderstood, and the overlap with DoLS is still developing.

   - There are situations where people are assessed as ineligible for DoLS (within the scope of the MHA and objecting to treatment) and subsequently assessed as ineligible for the MHA. This is becoming known as a “mini Bournewood gap”. Supervisory bodies are advised to develop protocols to address this. The WMRDLG has developed a protocol for the region and this has been shared with the national ADASS mental health lead.

   - To support the protocol the WMRDLG has also reviewed the Mental Health and Eligibility forms used by DoLS Mental Health assessors, s12 doctors were involved in this review and the new form is currently being piloted. There is within this form a requirement that a MHA assessment is requested in order to ensure the best protection for people.

   - There is an identified dedicated s12 lead in the West Midlands to work alongside the DoLS Leads and regional training is organised jointly for BIA’s and MHA’s. This involves an element of practice and has contributed to better working relationships and improved quality of reports.

   - Joint training is needed between BIA’s, AMHP’s and DoLS MHA’s to ensure learning takes place from each perspective.

   - Some BIA’s find decision making difficult that if they do not specialise in Mental Health.

   - There are issues regarding resources – often when someone presents with challenging behaviour – where they can be accommodated and what can be put into place for their support is led by what resources are available.

**Devolved administrations and international context**

1. **Is the MCA compliant with the United Nations Convention on the Rights of Persons with Disability (CRPD)? Are there lessons that can be learnt from the CRPD for the successful implementation of the MCA?**

   - There have been issues raised questioning whether DoLS are incompatible with Article 14, liberty and security of the person, as it states ‘the existence of a disability shall in no case justify a deprivation of liberty.’ The question is does DoLS authorise deprivation of liberty on the basis of disability i.e. mental disorder?

   - DoLS authorises a deprivation of liberty on the basis of best interests. The person needs to lack capacity for this decision due to an impairment or disturbance in the functioning of mind or brain. They also need to have a mental disorder.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
• It can be argued that the requirement to have a mental disorder is an unnecessary requirement and the safeguards would have the same effect if they were operated purely on the MCA definition of impairment or disturbance in the functioning of mind or brain. This is of course qualified within the MCA as not to be made simply by reference to age, disability, behaviour and appearance and so on.

Complied by Lorraine Currie, Chair of the West Midlands Regional DoLS Leads Group on behalf of the following Local Authorities -
Birmingham
Coventry
Dudley
Herefordshire
Sandwell
Shropshire
Solihull
Staffordshire
Stoke
Telford and Wrekin
Walsall
Wolverhampton
Worcestershire

7 October 2013
### Standards for Mental Capacity Act and Deprivation of Liberty Safeguards (MCA and DoLS).

The Standards are grouped into four main themes, which are divided into sub themes.

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This theme looks at what difference to outcomes for people there has been in relation to MCA/DoLS and the quality of experience of people who have used the services provided.

This theme looks at the overall vision for MCA/DoLS , the strategy that is used to achieve that vision and how this is led and commissioned.

This theme looks at service delivery, the effectiveness of practice and how the performance and resources of the services, including their people, are managed.

This theme looks at the role and performance of partnerships, including the Health and Wellbeing and Safeguarding Adults Board and how all partners work together to ensure high quality services and outcomes.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
A) Outcomes for and the experiences of people who use services

This theme looks at what has actually been achieved as regards MCA/DoLS and the quality of experience for people who have used the services provided.

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<td>1.1 People’s rights are effectively safeguarded in the community and in establishments such as care homes and hospitals.</td>
<td>There is a shared approach to outcomes with the council, NHS, providers, the Office of the Public Guardian, the Court of Protection, police and other partners.</td>
<td>There is an emphasis on outcomes throughout all strategies, plans and progress reporting and in interviews.</td>
</tr>
<tr>
<td>1.2 The partners’ approach to MCA/DoLS clearly has an outcome based focus</td>
<td>The public is becoming increasingly aware of the and using Lasting Powers of Attorney and advance directives</td>
<td>Focus group with people who use services and carers.</td>
</tr>
<tr>
<td>1.3 People are supported to realise positive outcomes relation to their finances, accommodation, safety, relationships and health and wellbeing</td>
<td>Outcomes are consistent, regardless of how old people are, whatever their disability or mental health problems, who pays for their care and their Fair Access to Care Services (FACS) eligibility criteria</td>
<td>Performance reporting includes outcomes measures.</td>
</tr>
<tr>
<td></td>
<td>Partners and providers use MCA and DoLS to safeguard people’s rights</td>
<td>Case files.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Health and Wellbeing or Safeguarding Adults Board reports.</td>
</tr>
</tbody>
</table>

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
A) Outcomes for and the experiences of people who use services

This theme looks at what has actually been achieved as regards MCA/DoLS and the quality of experience for people who have used the services provided.

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<tbody>
<tr>
<td></td>
<td>People experiencing MCA/DoLS processes are treated sensitively and with dignity and respect.</td>
<td>Board level reports, including to the council, CCG and NHS trusts</td>
</tr>
<tr>
<td>2. People's experiences of MCA/DoLS</td>
<td>Independent Mental Capacity Advocates are used for people who are (or may have been) experiencing abuse, and for people where accommodation changes, serious medical treatment or other significant life affecting changes are under consideration</td>
<td>Practice observation</td>
</tr>
<tr>
<td>2.1 Partners have achieved high levels of expressed positive experiences from people who have used MCA/DoLS services and their relatives/significant others</td>
<td>Outcomes are defined by the individuals concerned or their Best Interest Assessor.</td>
<td>Aggregated reports from reviews</td>
</tr>
<tr>
<td>2.2 Partners fully engage people who use services in the design of its services</td>
<td>Best interest assessments take full account of the range of people's circumstances in order to draw person centred conclusions.</td>
<td>Protocols, strategies, examples of user involvement</td>
</tr>
<tr>
<td>2.3 Delivery accords with the public sector Equality Duty</td>
<td></td>
<td>Forms and protocols that use respectful language</td>
</tr>
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<tr>
<td></td>
<td>Deprivation of liberty safeguards are applied where appropriate and an individual lacks capacity</td>
<td>Policies and procedures</td>
</tr>
<tr>
<td></td>
<td>There are services available to support carers, to support the improvement of relationships, and for abusers to address their behaviours where appropriate</td>
<td>File audits</td>
</tr>
<tr>
<td></td>
<td>Wider family members, friends or neighbours are engaged in MCA/DoLS except where this would not be appropriate</td>
<td>Management information</td>
</tr>
<tr>
<td></td>
<td>Deprivation of Liberty Standards (DoLS) reports</td>
<td>Deprivation of Liberty Standards (DoLS) reports</td>
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<td></td>
<td>IMCA Reports</td>
<td>IMCA Reports</td>
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<td>BIA Forum</td>
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### B) Leadership, Strategy and Commissioning

This theme looks at the overall vision for MCA/DoLS; the strategy that is used to achieve that vision and how this is led at all levels in the organisations involved.

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<tbody>
<tr>
<td><strong>3. Leadership</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3.1 There is recognised and active leadership by the council as the supervisory body</td>
<td>Senior Councillors, Non-Executives and key senior officers communicate how MCA/DoLS contributes to the wellbeing of individuals and communities</td>
<td>Leadership responsibilities have been allocated</td>
</tr>
<tr>
<td>3.2 There is joint and co-ordinated leadership with and by other key partners</td>
<td>Officer leaders communicate clearly the legislative frameworks within which MCA/DoLS sits</td>
<td>Cabinet, Scrutiny and NHS Board reports</td>
</tr>
<tr>
<td></td>
<td>Councillors and officers are knowledgeable about MCA/DoLS and keep abreast of local and national developments and learning, including enquiries, serious case reviews and reports</td>
<td>CQC and local Healthwatch reports</td>
</tr>
<tr>
<td></td>
<td>Partners actively champions the key principles as set out in the public sector equality duties on age, race, gender and disability</td>
<td>Stated cross-party support for the improvement of MCA/DoLS</td>
</tr>
<tr>
<td></td>
<td>Leaders are supported by appropriate training</td>
<td>Minutes of the Health and Wellbeing Board, SAB, Community Safety Partnership etc</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Examples of support and training for leaders</td>
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<tr>
<td><strong>4. Strategy</strong></td>
<td>4.1 Safeguarding includes MCA and DOLS and is embedded in corporate and service strategies across the council and partners</td>
<td>The Adult Safeguarding Policy and MCA/DoLS Policy dovetail with each other.</td>
</tr>
<tr>
<td></td>
<td>The process of developing strategies has been inclusive and includes the partners, providers, voluntary and community sectors, and people using services etc</td>
<td>Commissioning and contracting documentation</td>
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<tr>
<td></td>
<td>There is a Joint Strategic Needs Assessment with robust information about the needs of the full range of vulnerable adults</td>
<td>SAB reports</td>
</tr>
<tr>
<td></td>
<td>The council and NHS know what the views and experiences of people who have used services are and has incorporated these in its vision, strategies, plans and priorities. These are also incorporated into commissioning processes</td>
<td>Policies and procedures</td>
</tr>
<tr>
<td></td>
<td></td>
<td>The vision is articulated by the leaders and all employees across the Council and by its partner organisations</td>
</tr>
<tr>
<td>4.2 The council and NHS have a clear vision, priorities, strategies and plans for MCA/DoLS that is shared with key partners including the police and providers</td>
<td></td>
<td>Joint Strategic Needs Assessment (JSNA)</td>
</tr>
<tr>
<td><strong>5. Commissioning</strong></td>
<td>5.1 The council and its partners commission safe and cost effective</td>
<td>Commissioning and contracting (by the council and NHS) sets out quality assurance and service standards that safeguard people and promote their dignity and control. Clear expectations and reporting</td>
</tr>
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<tr>
<td>services</td>
<td>requirements are placed on providers</td>
<td>Management and SAB reports</td>
</tr>
<tr>
<td>5.2 The council and its partners have developed mechanisms for people who are organising their own support and services to manage risks and benefits</td>
<td>Contract monitoring has a focus on MCA/DoLS</td>
<td>Case files</td>
</tr>
<tr>
<td></td>
<td>Commissioning and contracting with regulated providers includes Care Quality Commission (CQC) registration guidance in relation to MCA/DoLS</td>
<td>Provider contracts</td>
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<td></td>
<td>Reporting across providers is tracked and under or over – reporting patterns addressed</td>
<td>DoLS application records</td>
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<td></td>
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<td>Forums/ meetings</td>
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</table>
C) Service Delivery, performance and resource management

This theme looks at how services are actually provided, including the involvement of people using services, and how the performance and resources of the services are managed.

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<tr>
<td><strong>6. Delivery and effective practice</strong></td>
<td>The council and NHS can clearly demonstrate good policies, practices and procedures in the delivery of MCA/DoLS, which are understood and followed by all professions and by staff at all levels</td>
<td>Practice observation</td>
</tr>
<tr>
<td></td>
<td>Providers, the voluntary sector, all council and partner staff are clear what MCA/DoLS is and how to respond to it.</td>
<td>Policies and procedures and the awareness and utilisation of them by staff</td>
</tr>
<tr>
<td></td>
<td>Providers have clear access to information and advice and are responded to effectively</td>
<td>Guidance for staff and partners (including such tools as flow charts)</td>
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<td></td>
<td>It is clear that the 5 principles of the MCA are embedded in practice</td>
<td>Information and advice for the public</td>
</tr>
<tr>
<td></td>
<td>DoLS applications and supervisory body responses are timely and proportionate</td>
<td>File audits</td>
</tr>
<tr>
<td>Care and Health Services ‘Put People First’ and safeguard them</td>
<td></td>
<td>Interviews with service users and their families/carers</td>
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<td></td>
<td></td>
<td>Any staff surveys</td>
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<td></td>
<td></td>
<td>Staff views of support from MCA/DoLS and safeguarding specialists</td>
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<td></td>
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<td>OPG and CoP papers</td>
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<td></td>
<td></td>
<td>Evidence of MCA/DoLS compliance</td>
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<tr>
<td></td>
<td>Professionals understand and respond to people whose capacity fluctuates</td>
<td>with safeguarding adult cases</td>
</tr>
<tr>
<td></td>
<td>Professionals demonstrate the ability to make sound assessment of decision and time specific assessments of capacity in order to support decisions that are in the individual’s best interests</td>
<td></td>
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<tr>
<td></td>
<td>Safeguarding staff are aware of and respond to people in circumstances where their capacity is compromised because of the undue influence of an individual or environment</td>
<td></td>
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<tr>
<td></td>
<td>Care and protection plans are clear and incorporate requirements for monitoring and review.</td>
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<tr>
<td></td>
<td>There are regular reviews that identify any potential MCA/DoLS</td>
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<tr>
<td></td>
<td>concerns</td>
<td></td>
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<td></td>
<td>There is no compulsion for any course of action except within the framework of the law, including the Mental Health and Mental Capacity Acts</td>
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<tr>
<td></td>
<td>Information sharing protocols are clear so that information is shared appropriately across agencies. Information sharing behaviour is consistent with the protocols.</td>
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<tr>
<td></td>
<td>Staff are confident in using these arrangements and are supported by specialists</td>
<td></td>
</tr>
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<td></td>
<td>The Office of the Public Guardian and the Court of Protection are used to safeguard people’s rights</td>
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<tr>
<td></td>
<td>There is evidence of challenge and learning (for instance in</td>
<td></td>
</tr>
</tbody>
</table>
### C) Service Delivery, performance and resource management

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</thead>
<tbody>
<tr>
<td></td>
<td>relation to challenging DoLS applications, BIAs, deputies etc).</td>
<td></td>
</tr>
</tbody>
</table>

#### 7. Performance and Resource Management

- **7.1** Services are held accountable through performance measures, including quality measures, towards the outcomes for people in the strategy.
- **7.2** There are sufficient, sufficiently knowledgeable and skilled staff employed in partner organisations or commissioned from external organisations to efficiently and effectively deliver the requirements of MCA and DoLS.

- There is a practice and performance management framework that runs across council and partner agency functions.
- Quality assurance systems incorporate MCA/DoLS and risk management, together with improved outcomes for people.
- Local workforce and training plans provide that people with the right skills for MCA/DoLS.
- There are mechanisms to enable staff to share risk and difficult decision making on a professional basis.
- All staff have regular supervision that facilitates good decision making support and an appraisal scheme that operates at all levels and which addresses development and performance.
- There is cross-sector training and development including equality awareness training.

- A suite of indicators including quantitative and qualitative measures of performance that is reported regularly to senior and team managers.
- Summaries of training activity.
- Skills and confidence as demonstrated in interviews and through file audits.
- Overview and scrutiny agendas and reports with evidence of follow up.
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<tr>
<td></td>
<td>There is a range of systems that improve the quality of services on the front line, including through quality assurance, performance reporting and mechanisms</td>
<td>Training material</td>
</tr>
<tr>
<td></td>
<td>A learning culture is evident. Partners learn from both best practice and from things that don’t go well. Serious case reviews are used as the basis of improvement for the future</td>
<td>Quality assurance framework</td>
</tr>
<tr>
<td></td>
<td>Arrangements for the role and process of overview and scrutiny are clear and effective, with council resources devoted to it to ensure effectiveness.</td>
<td>OSC report</td>
</tr>
</tbody>
</table>

D) Working Together

This theme looks at the role and performance of the local partnerships and how all partners work together to ensure high quality services.

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<tbody>
<tr>
<td>8. Health and Wellbeing,</td>
<td>8.1 There is multi-agency commitment to safeguarding</td>
<td>Reports and minutes</td>
</tr>
<tr>
<td></td>
<td>There is a clear arrangement for co-ordinating the work of partners in relation to people who lack capacity (for example, a Safeguarding Board that demonstrates effective leadership and manages the delivery of MCA/DoLS policy and practice across all agencies, with</td>
<td></td>
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<tr>
<td><strong>Safeguarding Adults Board and other partnership arrangements</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8.2. There are a range of partnership working initiatives in the area to ensure that people who lack capacity are safeguarded.</td>
<td>representatives that are sufficiently senior to get things done</td>
<td>Council Executive and Scrutiny reports and minutes</td>
</tr>
<tr>
<td>8.3 MCA/DoLS is effective at all levels (prevention and intervention)</td>
<td>Partners provide challenge and support on the outcomes for and experiences of people needing services and the impact and effectiveness of service delivery to its member organisations</td>
<td>NHS Trust, CCG, Police Authority and other Board papers and minutes</td>
</tr>
<tr>
<td>Partners (senior executives, non-executives, councillors and others from the key partners, including commissioners, regulators, providers and organisations representing disabled and older people and patient and public interests) work together to ensure that the right of people who lack capacity are safeguarded</td>
<td>Work has taken place across public and commercial sector bodies to raise awareness of the abuse of people who lack capacity and to safeguard their financial and health and welfare interests</td>
<td>Interviews and focus groups</td>
</tr>
<tr>
<td></td>
<td>There are mechanisms in place to ensure that the views of people who are in situations that make them vulnerable, and carers, inform the work of the boards</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Partners work in an atmosphere and culture of cooperation</td>
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TUESDAY 22 OCTOBER 2013

Members present

Lord Hardie (The Chairman)
Lord Alderdice
Baroness Barker
Baroness Browning
Baroness Hollins
Baroness McIntosh of Hudnall
Lord Patel of Bradford
Lord Swinfen
Lord Turnberg

Examination of Witnesses

Terry Dafter, former Joint Chair of the ADASS Mental Health Policy Network, and Lorraine Currie, Commissioner for MCA/DoLS Manager at Shropshire County Council

Q172 The Chairman: Good morning, Mr Dafter and Ms Currie. Thank you very much for coming along to give evidence and for the written submissions that you have made to the Committee. They are very full and very interesting. Hopefully we can explore your evidence in a little more detail. You will be aware that this evidence session is recorded and broadcast. Mr Dafter, your submission refers to the fact that the sector is moving towards a clearer understanding of what constitutes good practice. What is good practice in the implementation of the Act and what is the role of directors of adult social services?

Terry Dafter: Directors of social services have to take a strong lead around the Mental Capacity Act. If they do not model it and encourage its use, and encourage a culture within their organisations in which social workers and other practitioners feel able to practise the Mental Capacity Act and be supported in making some very
difficult decisions sometimes, I think we are failing in our responsibility. For me, good practice within a local authority would be demonstrated by a clear commitment from the director in support of it. There should be some embedding of the Mental Capacity Act in social work practice; good, comprehensive training and awareness-raising among staff; and elected members should understand and be fully aware of the implications of the Act. There should be a proactive approach to training in the sector, especially the independent sector and partners in health, around the implications. Carer groups, user groups and so on should equally be given full awareness of the Act and its implications for them. There should be a very open and transparent approach to the Act, and a very public commitment to it, because it embraces very strong values and a good value base for a way forward in its thinking around individuals’ vulnerability and how we should work with those individuals.

The Chairman: Obviously, all this requires funding, and we are aware of the difficulties of public sector funding at the moment. In your submission, you refer to the grant under the Act still being made available and the question of ring-fencing, which is always a vexed problem in public sector finance.

Terry Dafter: Indeed, absolutely.

The Chairman: Even if there is no ring-fencing by local authorities, could directors not manage their budget in such a way that gives priority to the Mental Capacity Act to achieve these objectives that you mentioned?

Terry Dafter: Absolutely. It was not tongue in cheek; it was simply that I think that all directors like ring-fencing because it means they do not necessarily then have to be vulnerable to losing that funding within the general revenue support grant. If it is ring-fenced, it is ring-fenced, and you can identify it and secure it corporately. In fact, much of what I have described already does not necessarily have to inflict a huge extra cost. Most local authorities have staff development teams and training teams now, so it is a matter of prioritising that work. The leadership comes from the post and the director; the elected member’s leadership should be there. We all have communications budgets and partnership arrangements with colleagues. Although that funding is helpful and identified as important, I would be contradicting myself if I were to say that it should not be part of mainstream delivery in the local social services department. It should not rely on extra funding to do it, because it should be key and integral to our way of working.

Lorraine Currie: Where we have managed to keep the MCA grant discrete, we can achieve a lot for a little by working together. It is not ring-fenced, but in some local authorities we have managed to keep it discrete, and we can achieve a lot where that results in a lead role—for example, someone in my role—across local authorities, often by working in partnership with health, because many of us have joined our budgets together. The importance is of seeing that grant as very discrete, seeing the reason for it and the function of it in providing all the things Terry has just said, and seeing where we can work with other partners to achieve this. That is the important message.
Q173 Baroness Hollins: Good morning. Social work professionals have suggested in their evidence to us that, in contrast to the Mental Capacity Act, safeguarding is prioritised within social care. We have heard reports that the Mental Health Act is more widely followed than the Mental Capacity Act. I wonder whether you agree with that, why that is and what lessons could be learnt for the leadership of the implementation of the Mental Capacity Act.

Lorraine Currie: It is a very difficult question to answer, because it depends on who has given that evidence already. Within the mental health field, the Mental Health Act is better understood, but it is a very specific field and very narrow to a very specific group of people. The professionals involved in that are clearly identified and they understand their roles very well. The Mental Capacity Act, however, is a wonderful piece of legislation and impacts on every aspect of the local authority’s work and every aspect of life almost, if I can go that far, from the pharmacist in the pharmacy to people in the library. It is a very wide, overarching piece of legislation. Generic social workers have a better understanding of the Mental Capacity Act in partnership with safeguarding because they are key roles and values for social workers. Most generic social workers would step to one side the minute there is a suggestion of the need for the Mental Health Act, because they would see that as the role of AMHPs and psychiatrists. Over time, though, we are managing to convince them that their role does involve the Mental Capacity Act in everything that they do.

Baroness Hollins: Are there lessons to learn from safeguarding and the way that is understood?

Lorraine Currie: There are lessons to learn in how it is prioritised, yet the Mental Capacity Act has a stronger legislative framework than safeguarding. Safeguarding is given a very good position, clearly because of the ramifications when things go wrong. The danger from my perspective is that the Mental Capacity Act work is easily subsumed within the greater work of safeguarding and its distinctness is lost. It is one of the things that we really need to guard against: that it is seen as discrete. There is an overlap, but it is a very discrete piece of work. They complement each other and can enhance each other, but it must be seen as discrete or it loses any significance.

Terry Dafter: I would also add that, from a directors’ point of view, safeguarding, along with the budget, is one of the two areas that we are most vulnerable on. If we get something wrong in safeguarding, that is a very big matter for us personally in our roles. There is an apparatus and a system in existence around safeguarding that has built up over the years in the light of particular events, scandals and so on. There is an apparatus, set guidance and processes that have been established in order to try to protect people who are vulnerable in those situations.

Similarly with the Mental Health Act and so on, people have been detained under the Mental Health Act for some time—I started 30-odd years ago and I was sectioning people under the old 1959 Act, then the 1983 Act and so on. In a sense there is a history around the Mental Health Act that is longer than the Mental Capacity Act, which is much more recent and much broader. The lesson we can learn from safeguarding is having good systems in place that everybody is aware of and can be trained in, and that people are clear about what their role is.

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Possibly the lesson from the Mental Health Act is actually the training that is given and the fact that to practise under the Mental Health Act you have to have extra training post-qualification. You can only practise the Mental Health Act and detain people under it if you are an AMHP. I am not saying that you should necessarily have something similar for the Mental Capacity Act, but it is a good model. It demonstrates that there is a need for post-qualification training. This is sometimes about dealing with quite complex matters, maybe balancing the views of a family with the views of a person with a disability, and trying to weigh up various views and trying to get an independent view on what is best for that person. It is not easy work, and you do need post-qualification support and training in that work to feel confident and supported. We can learn something from both.

Q174 Baroness Hollins: If the culture is a little risk averse and trying very hard to protect, is there a balance to be struck between that and enabling people?

Terry Dafter: There is.

Baroness Hollins: How do you get that balance better? Are you suggesting that training is most important or that systems are the most important?

Terry Dafter: It is really important. We have come a long way in public services and social services. When I first started, there was a very paternalistic approach. When I was a social worker in a big city 30 years ago, everything was council-run; everything you got was on our terms and on whether I said so, crudely. The assessments were very much for council services on council terms. We have moved an awfully long way from that now. Personalisation and giving people more control is very much moving in a direction where that power is handed to the individual with support and we say, “We will support you to make your own choices”. Sometimes those choices can be quite contentious, but nevertheless it is a good trend and one to be welcomed.

I feel it is part of a social role and has been for a long time, ever since I have known it, to balance the need to try to encourage people to make choices, to sometimes encourage them to make the wrong choices or difficult choices, and sometimes to balance risk when other professionals are saying, “Hang on a minute. That old lady down the road is wandering. Why aren’t you doing anything about it? Why isn’t she in a home?”. Actually, as social workers we are instinctively usually saying, “No, that’s what she wants to do. She’s happier, and the alternative would be more detrimental for her”. That is what we still have to encourage. Social workers in my organisation, if they make those decisions, should expect my full support and backing. As long as they have not behaved recklessly and they are not behaving inappropriately, that is the sort of culture we should be encouraging. If you have a risk-averse culture, though, and you are forever wondering what is coming around the corner or what the local press is going to say about something — this certainly comes through in personalisation and what people spend their money on, and in this — then you can swing it too much the other way, and I think that is very sad.

Q175 Lord Patel of Bradford: Your answers have been really helpful. There are boxes ticking in my head of how we separate all this. We have asked several
times about the relationship between the Mental Health Act and the Mental Capacity Act. Your answer was very helpful on the two or three things. One is that there is a whole issue about risk. Under the Mental Health Act, you are taking people's liberties away; it is very specialist and there is a team of specialist people. Safeguarding probably mirrors that to some extent. As you said very clearly, the Mental Capacity Act is everybody and everywhere. There is a small bit, though, where you are making that decision finally for somebody: whether we should have the same level of specialist team built in that is similar to the Mental Health Act and safeguarding. That is one big thing. I suppose they are two different beasts in a sense, but somewhere they cross over.

**Lorraine Currie:** Do you mean a specialist team in terms of assessing capacity or do you mean for the deprivation of liberty safeguards?

**Lord Patel of Bradford:** I think both in some way. I know it is difficult because it is such a long continuum, but it feels like these are based on risks, anxieties for people; they are specialist teams and they know their business.

**Lorraine Currie:** This is developing within practice. There are many different levels of decision-making with the Mental Capacity Act, and practitioners do really need to be encouraged in their confidence to make decisions. The big difference between safeguarding and the Mental Capacity Act is that you act alone, pretty much. It may be as a result of a multidisciplinary meeting, but ultimately one practitioner puts their name to their assessment. That is the difference compared with the confidence that people gain from safeguarding.

Our director is very clear in supporting a protocol for who can make which decision at which level, because we have to say that not all staff are equally competent. Sometimes if you have a lot of factors, a high level of risk and safeguarding concerns, you need an experienced practitioner. Those kinds of protocols are very helpful in not leaving everybody just feeling that they are at sea. The code of practice only talks about best-interest decisions, but more and more we do have best-interest meetings—not for the everyday “Which socks do I wear today?” but for the more complex decisions. We would expect that to be an information-gathering exercise in a multidisciplinary way, with one person then taking responsibility for decision-making, but fully supported by family, carers and everyone else who contributes to that process.

**Q176 Baroness Browning:** I just wanted to ask you about your reply to Baroness Hollins about getting this balance right between enablement and protection. It was part of the Act that people should, like everybody else, be able to make a wrong decision. Could I ask you just to reflect upon the fact that, if one of us makes a wrong decision that has quite serious consequences down the track, we are at least able to rationalise it and learn from that mistake? For many people without capacity, or for people with fluctuating or partial capacity—I am particularly thinking here of young adults with autism or learning disabilities—how do you get the balance right there? The consequences could be quite dire and they do not have the ability like us to perhaps learn from it and recover from it.
Lorraine Currie: The Act offers an answer to every problem or challenge. This is why it is a culture change; we are trying to embed values into practitioners. That is very much about supporting the person’s ability to make a decision, and accepting that those sometimes will be risky and we do not like them, we do not like to be challenged, and I personally think it is good that we have been challenged as practitioners. That does not mean we draw a line in the sand, though, and say, “Okay, you are making that risky choice, so you’re on your own”. We have just supported a 99 year-old woman in the last week to return home from a care home. Everybody thinks this is a very risky decision. It has not been made easily; it has been properly made sitting on the principles of the Mental Capacity Act, and she will be supported in that. We also will have a back-up plan for if that risky decision fails.

It is about generic social work practice—the meat and drink of social work practice is to support people—and not saying, “If we don’t like your decision, we won’t support you”. Obviously, there are some decisions and ways people choose to live that we are not easily able to engage with, but we still offer the whole range of social work support to people. We ensure that that decision is multi-disciplinary, that there is a back-up plan and that, as far as possible, it is resourced for the person’s quality of life and to respect their choice.

Baroness Browning: I have just been driven by my 100 year-old uncle. I have to say all those things came in to my mind.

Q177 Baroness McIntosh of Hudnall: You have pretty much covered all the things that I was going to ask you directly, but I have two other questions. First of all, I think if I were losing or lacked capacity, I would very much like to be where you are, because it strikes me that both of you have expanded both in theory and in practice exactly how the Act should work and how it evidently does work where you are practising. It seems to me, though, that the evidence we have demonstrates, at least anecdotally, that that is not universally the case. I just wonder whether I could pull out this thread of the default towards protection against litigation or protection against reputational harm. Probably just on human grounds, it feels to me to be where people who are less confident about how to use the Act than you both are might feel themselves drawn towards. Can you just tell us what you think could be done to help the people who are less on top of it than you are?

Lorraine Currie: In Shropshire, we had some money from the Department of Health that we bid for a few years back to do an audit of the Mental Capacity Act in practice. We learnt an awful lot from that. We learnt that our practitioners did not feel confident; they had the head knowledge, but they did not feel confident in practice. We were able to change what we offered. We were able to change our training, we were able to give them clear guidance about what is expected of them at what level, and we were able to look at a staff competency framework. All those things and many others that we have put into practice can be applied regionally and nationally.

Certainly, the work Terry and I have done has been because of regional networks coming together. I chair the regional DoLS Leads Group for the West Midlands, and we are sharing practice. For example, we are trying to look at the variance in figures across the region, how we can influence that and what we can do to try to move

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towards consistency: having a lead person in post and then having that person able to relate to wider networks, local implementation networks, regional networks and then into something like the ADASS network that we have been discussing. We have changed the world while we have been in the waiting room.

Terry Dafter: We have sorted it all out.

Lorraine Currie: We are discussing the good practice that is out there and how we can bring that into play more regionally and nationally. These are things that can be done very easily and simply to help improve practice across the board.

Baroness McIntosh of Hudnall: Can I just pursue that a little bit? Obviously, within your own local authorities, I would infer from what you say that you have succeeded in taking people along with you to the point where you can confidently say that you know what that best practice is and how to implement it. I assume that your colleagues who are not part of social work practice, who are in other bits of the local authority forest, can see what the benefits are and trust you. There presumably is a job to be done not just with your own colleagues but other people as well.

Terry Dafter: There is. We have been reflecting on this coming here today. ADASS and the Mental Health Network has a part to play here because good practice and having a good, structured approach to the Mental Capacity Act should chime and resonate with carers, users, families and so on. This is something that they would want social services to be like. I do not think they would want to be part of a service that is very overprotective and reactive in its approach. ADASS has not done enough, though, in demonstrating what a good model is, demonstrating how it could and should work, and then encouraging.

I went to Lorraine’s meeting as part of preparing for coming today. I was quite inspired because it was a group of people who all knew the Act absolutely off the tops of their heads. Part of the discussion was almost above my head at times, but it was a fantastic model because it involved peers, it was talking about practice, and it was sharing quantitative data: how many they had done, the percentage of people who applied who have actually been approved, the position on the ground, what evidence there was locally and how good practice could be shared. That network is strong in the West Midlands, and it is pretty strong in the north-west; it is not as strong in some other parts of the country.

ADASS needs to, and will as a result of this, encourage much more networking and encourage other networks across the country to begin to act and reflect in a similar way. In a sense, it is a shame. You could argue that it is inevitable, and I do not want to sound defensive because I am not. It is relatively new, it is relatively complicated, and in some areas it has frankly been given more priority than others. In some areas, they have had other priorities to think about. Nevertheless, beginning where we started, I do not think there is any model or framework that would say, “This is good practice. This is really what you should be doing, these are the sorts of areas you should be covering, and let’s actually share that together”, Sometimes directors are only too happy to have an off-the-shelf framework to say, “Well, actually that’s great”. Let us think about how we are going to benchmark...
ourselves against some of these approaches. I would hope that ADASS can take more of a lead here and begin to share and model good practice around this. Frankly, where it is working well, it is working very well and people are best served. We should try going for that nationally.

**Lorraine Currie:** We, the people in practice, lost the national and regional leads from the Department of Health. We really missed that; it went too soon. We had regional and national leads for the Mental Capacity Act; the deprivation of liberty safeguards swooped in, and pretty soon after that we lost that centralised lead. We have not really had anywhere to look to answer the questions: what is the definitive interpretation of this legislation?; how do you actually want us to act in this situation?; is it good to have a lot of DoLS requests or is it actually bad to have a lot of DoLS requests? We get caught up in figures and we have not yet really sat down and said, “Yes, we have a lot, but is that good or is that bad?” Is it better to look at how many we are authorising per number in or look at that against our population. There is so much data, and yet we are missing that very central direction. That is the one thing that would really help us: a clear focus on having the lead in each authority to carry on that work.

Q178 **The Chairman:** Do you think the impetus should come from central government then on the national rollout of your good model? I know you have said that ADASS should do more, but should there be some encouragement from central government?

**Lorraine Currie:** Yes, it is the encouragement. There would be an imperative to action if there were a very clear direction to where we are heading and what we should be looking to achieve. It is very easy then for directors to prioritise that and to galvanise to action, rather than people like me trying to agitate everybody into action.

**Terry Dafter:** Of course, we are not inspected as a local authority anymore. I am sure two or three years ago, when there were star ratings and CQC used to come in—or CSCI as it was—and gave us a star rating based on a range of performance and performance indicators. I am sure this would have been integral to their evaluation. Of course, we are not anymore, so we are relying much more now on peer reviews, peer support and so on. That is why I was mentioning ADASS, in a sense, as a vehicle for this, because in a way this is the new world of evaluating the local authority on social care.

**The Chairman:** Can I just ask one final question on this? The Act does not require the routine reporting of decisions, so how do you actually monitor what is happening on the ground?

**Lorraine Currie:** In order to test the water in any way, the lead for the authority has to be proactive. There are various ways to audit. I can to some extent say what we do and what we do across the West Midlands. If documentation for assessing capacity, for example, across generic social work practice is part of the social work electronic systems that we all love, it is possible to do some monitoring of that and certainly to check very basic things like how many assessments and whether they were followed by best-interest decisions. We can do simple things. We can also

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look at the quality of them and do that regularly. In the West Midlands, certainly with DoLS authorisations, we have reviewed the forms, we have amended them and we have agreed West Midlands versions, so the forms should look the same anywhere in the West Midlands. We have also done that by working in practice with the best-interest assessors to look at what quality is in an assessment: what should be there and what makes good-quality assessments. The forms have then matched that. We have done that with our authorisers as well: what we expect from them when they approve these very serious decisions.

Now we are moving to a situation where we can do peer audit. In November across the West Midlands, we will share random selections of assessments with each other and comment on the quality, the content and the decision-making. That is just one area; that is the West Midlands. There are similar things going on, but it needs each area to initiate that itself. That is why there needs to be the focus on the person to take the lead and the dedication to the budget to do that.

Q179 Lord Swinfen: Obviously the Mental Capacity Act is embedded into social care work, but how do you ensure that providers of care services, whether in residential homes or people’s own homes, comply with the Act? What concerns do you have about the workforce issues identified in that sector? You have poorly paid and unskilled staff with high levels of staff turnover. What implication does this have for the Mental Capacity Act?

Lorraine Currie: Again, I believe that it is about partnership working. There still exists in most places what was originally a local implementation network, and that has tended to go on to become some kind of operational network. We work with our partners in that: the care homes, domiciliary providers, the police, ambulance service, hospices and hospitals. They are all involved in those operational groups, and we share good practice and expectations with them. I certainly see it as part of my role as the lead to disseminate information to them to make sure that they are aware of changes, case-law decisions and just basic information. We produce posters and leaflets that we share with them—all those kinds of things.

Also, at the heart of our contract with care providers, we are certain that the MCA is embedded into the contractual requirements. It is easy to put that on paper, but we then have to test that in practice. We provide an awful lot of training because we have a dedicated role and a training role. The greatest take up is from the independent sector, because with the grant still being available, for the large part we have been able to make the training free for those people in the independent sector. That is a great encourager for them to continue to come along. Also, when there is that change of staff, which there is, we train a couple of thousand people each year from hospitals and care homes as well as the local authority. It is keeping that momentum going, because the Mental Capacity Act is ever changing. Our understanding of it is ever changing, and it evolves in different directions, so we offer them as much support as we can in order to ensure best practice.

Terry Dafter: I do worry about the sector for the very reasons that you have outlined. There is this huge turnover and staff problems. They are in competition with the retail sector and with a lot of other areas. Often the level of training and support is poor: you train 2,000 and 500 people move on within the year and you In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
have to start all over again. This is a problem in the care sector generally, not just in relation to the Mental Capacity Act. I do take your point that it is something that we have to be mindful of and aware of generally, not just around the Mental Capacity Act.

Lorraine has covered most of it. I think you do have to build it into your contracting arrangements; you have to make sure people are trained within that home and that there is leadership from the top—that the manager and the deputy manager are well trained and well versed in the Act. You have to check out the number of referrals you are getting per home and worry about a home that you do not necessarily get any referrals from and equally worry about ones where there is perhaps an overzealous application of the Act. You start to ask the people who monitor your contracts to bear those figures in mind along with other reporting figures that we take around the sector.

There is some relationship with CQC, of course, and monitoring standards through your local CQC office too, and taking a view with them. Equally, it is just talking to social workers and families about the kinds of receptions that they get if these sorts of decisions are starting to come to the fore. Are these organisations that are receptive to discussions around the Mental Capacity Act, that are not behaving defensively and that see it as something constructive? Are they organisations that encourage their staff to do the same? That is what you need to aim for, but I take the point entirely that it is a sector under severe strain and severe pressure. I do not have an answer to that, I am afraid.

Lord Swinfen: What sort of proportion of those working are from Europe and the world generally, rather than British? Do you have language problems as a result, and does this exacerbate the situation?

Terry Dafter: I could not comment too widely, because in the authority I cover it is not a big issue. It generally recruits locally. I am aware, though, that in neighbouring big inner-city areas it is more of a problem, and I think that is an issue in some parts of the country. I do not have the data to hand that could give you a comprehensive answer to that, but it is a problem in some parts of the country.

Q180 Lord Patel of Bradford: In respect of best-interest decision-making, you have touched upon a number of factors within the Mental Capacity Act. There are also a number of factors outside the Mental Capacity Act that have been identified. We live in harsher economic times, so there are the pressures on hospital beds and the costs of residential care versus home care. Is it naive to assume that somebody would not make a decision based on those external factors such as costs when you are doing best interests?

Lorraine Currie: In my experience, best-interest assessors are incredible professionals. This has been a new role and it has become a fantastic role. They are best-interest assessors working within DoLS, and there are wider questions about best-interest decisions in social work practice. Again, though, I have found that people make very wise decisions. The best-interest framework is about the way in which the decision is made, rather than so much focused on the decision itself. It
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All of us, though, are too aware that resources are finite and limited. We could probably describe a tailor-made service for every service user that we come into contact with, but that is not the real world. People are aware that best interest does not mean that you can have the best possible service that there is. As we have trained and as we train other assessors and social workers, we are trained to consider the options on the table. Sometimes those options are limited, and that compromises decision-making. That is absolutely true, and it would be wrong to deny that.

For some reason, locally we have recently had a number of DoLS referrals for people with neurological injuries. We found ourselves authorising perhaps three deprivations of liberty for the same person because we were unable or the staff were unable to identify appropriate rehab resources. That person may actually be deprived of their liberty in a more restrictive hospital setting because they are waiting for those resources to be available for them. You would not find a best-interest assessor in that context saying it is not in their best interest to be there because the end result of that would be the person could leave the hospital to no resources. It is striking the balance between the person’s safety and having some aspiration about what is in the person’s wider best interest within available resources. I think people generally do balance that well. I think we have been very well trained in local authorities that we have to take account of resources.

Terry Dafter: It would be naive to suggest that the resources available to somebody within the local authority budget or the health budget are not a factor in making those decisions. You cannot avoid that.

Lord Patel of Bradford: Can I just ask another question? This is slightly wide of the mark, but you two have provided such clear answers to all the questions, I had to ask you. You might want to go away and think about it, but is there an issue around black and minority ethnic communities, whether it is overuse, underuse or anything you know in terms of what is happening about the Mental Capacity Act?

Lorraine Currie: I do not believe the data would bear that out, but again it is a very personal, quick response to your question. I do not know that we are very good at knowing what data we want to collect and why. I think perhaps we tend just to collect the usual, generic data. Certainly for DoLS we would collect the ethnic monitoring sheet, but I would not know whether we collect very good qualitative data about types of care homes, types of restraint, or whether certain populations within a generic area may be more likely to experience restraint. There may be some very good questions that could be asked, but I do not think anybody has asked them or collected the data. I may be wrong and there may be lots of research out there, but I am not aware of it.

Terry Dafter: I am happy to do some more work, and if there are any figures around that, I will send them in writing to the Committee.

The Chairman: That would be very helpful.

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Terry Dafter: I will have a look into it.

Q181 Lord Alderdice: You have been mentioning data and figures. We have been looking at the numbers of DoLS applications in regard to the number of people to whom they might be applicable. Do you find that managing authorities are able to identify a deprivation of liberty? Are you confident that applications are being made when they are needed? How do you explain what appear to be substantial current regional variations?

Lorraine Currie: Some managing authorities are able to identify a deprivation of liberty. It is very pertinent that we are sitting here today while the Supreme Court is trying to decide what it thinks deprivation of liberty means. We are expecting a lot of staff who possibly get paid £7 an hour to make decisions on a very complex subject.

I could not say I am entirely confident that referrals come in when they should do. I think we have to create a welcoming culture, where they are free to put in referrals, even for those to be found to be inappropriate. I personally would rather have those and find the person to be ineligible or the safeguards to be not applicable. I welcome that sort of dialogue with our managing authorities.

I think they hold a lot of fear of getting it wrong because the tariff has been set quite high for their applications. It is very much tied to training. Where we do training, usually an application will follow. There is confidence in the process itself, so once a care home or a hospital ward has made an application, they tend to feel more comfortable to make them again. We monitor our care homes very carefully; we know the ones out there who have not been on training and have not made any DoLS referrals.

It is a wide question to answer; the variations are there and we cannot get away from them. We collect data regionally, so we collect it across the West Midlands per 100,000 of population, which is slightly more informative, and we discuss that. If something stands out, we discuss that regionally between the leads groups. The number of referrals we have authorised sits at around 50% to 60% across the West Midlands, so we have moved from having great extremes to more consistency. I think that is because of the work we have done collectively in looking at good standards.

This process needs to start in the care homes and in the hospitals, and it almost should be the other way round, where if we were out there and we were required to inspect them and to say whether they needed to put in requests, then maybe we could be asked to comment on our confidence. While it sits with them, though, it is about how much formal and informal training we provide them. We visit them and we go out and provide them with information. It is still very early, and it is again about having that centralised view of why there are so many variations across the country. I can speak for the West Midlands, but not for other parts of the country.

Lord Alderdice: Could I just press you a little as to how far you think it is to do with differences of need and how far it is to do with differences of training.

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expectation or personalities that are key to it, or whatever? You will find that there are different levels of problems in different regions; it is different in urban areas and rural areas for example. How far is it to do with those kinds of differences and how far is it to do with other kinds?

**Lorraine Currie:** It is like the layers of an onion. Again, it is about different cultures; the culture in care homes often needs to change. The Mental Capacity Act is the forerunner of establishing good practice. If we get our care homes to implement the Mental Capacity Act properly, look at restraint and restriction, the techniques they use and the tactics they use, and the types of support they need to cope with some very challenging situations, that may lead on to helping them to encourage staff to know when this has gone beyond the Mental Capacity Act, what they can do under Section 5, and when it has moved in to DoLS.

**Terry Dafter:** It is interesting, because I was talking to a director from a large county who was saying there were variations even within his county in parts of the county where there is quite a high use of DoLS and other parts where there is very little. It is not just regional; it is almost within big counties as well. I do think this is something we need to do more work on because, as Lorraine describes it, it is partly to do with training and awareness, but it is also need. There may be some homes where it just would not be at all appropriate to make any referrals because most people have capacity. Again, I think this is just something that we need to do more work on, and begin to have more of a dialogue around this and get underneath some of this data.

Something is going on, and we are all making assumptions around what that might be, but, again, part of the proposal that we are considering within ADASS is to actually try to do a piece of work around this to try to unpick this more. It is not right; there is something going on and we need to get to the bottom of it.

**Q182 Baroness Browning:** How do local authorities ensure in practice that their role as a supervisory body, where for example you assess applications for DoLS, is independent of their role in relevant decisions on care? At that point, where there is almost a crossover between the two responsibilities, is there a particular process or something that is put in place to demonstrate transparency?

**Lorraine Currie:** The processes sit quite separately within most authorities. There is a crossover sometimes, in that the best-interest assessor may also be a care manager. That is not always the case. For example, we have substantive best-interest assessors, so they are not involved with care management. The DoLS referrals would come in and there is a DoLS process that will go along a parallel line. It will not necessarily link with care management other than the required consultation and communication.

The difference comes at the end, where quite often the people who are authorising those DoLS requests may be senior managers within adult social care. They will have knowledge and they will have experience of care management for that individual. Sometimes a number of these individuals will be funding their own care; they may not be funded at all and not have had any care management, or minimal care management.

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We have actually found the loop works quite well the other way round. Generally, the best-interest assessor may pick up some inadequacies in care management or they may pick up that perhaps the MCA has not been as properly considered as it should have been. They can then work to influence that back round into care management to the benefit of the service user. We have found some real benefits in that, rather than sensing any kind of constraint in the role. I have found it a very positive thing, but I think there is a requirement to keep a distinction between best-interest assessors and authorisers acting—in the case of BIAs—as independent professionals and not being constrained by their care management role.

**Q183 Baroness Barker:** From the start, there has been a suspicion that the local authorities being the bodies that commission any care services would be a weakness in the Bill, because they would be reluctant to find against the body that commissions and employs them. In light of your experience, do you think that criticism was right?

**Terry Dafter:** I would be worried if that were the case, because I think generally we commission a number of services that are there to help quality-control what we are doing. I have an independent chair of my adult safeguarding board who spends a lot of time telling me off for the failings of the board and what it should be doing. I would not dream of not renewing his contract; it is what I pay him for. It is the same with this. You would expect healthy challenge and healthy feedback on the way that you are operating, but that should be helpful. It is part of the quality control of your department and your directorate. You would not want somebody to say it is all okay, because it is never all okay, is it? You are never there; there are always issues that need resolving. In a sense, I feel it is inherent in the role. We commission advocacy services, independent chairs for safeguarding and so on. I do not think it is unique within the kinds of services we commission sometimes. I just think you need to try to treat it healthily and see it as a healthy challenge, not something that is disreputable. It is what you pay for.

**Lorraine Currie:** We retendered our contract recently, and that commissioning process throughout was not based in any way on: “How many times they have criticised us?”. We are looking at the quality of that provision, and to some extent the quality of that provision is how many times they have challenged us. It is a healthy relationship that we have with them, and we almost look forward to them raising things that we can address. We work in partnership with them, they are part of our operational and our regional networks, and we value the role that they have.

**Baroness Barker:** That is good to know.

**Terry Dafter:** That is definitely what I would hope.

**Q184 Baroness Barker:** Finally, access to justice is something that people are concerned about. There are lots of concerns about the speed and the capacity of people to get to the Court of Protection. People like BASW have suggested using more mediation IMCA-type services in order to speed things up. What do you say to that?
Lorraine Currie: We have said that we would welcome a tribunal system, for that being seen to be a quicker resolution for people. However, it is a very big and a careful decision to be made. The Court of Protection needs to be more accessible and cheaper. There is no other way really to say that. There are a number of possibilities out there. Removing the need for expert witnesses would make the whole process a lot cheaper. I am a BIA, and a lot of BIAs feel that we are experts in our field, and yet the minute that we step into the Court of Protection, experts are commissioned at huge cost. We need to remove the need for expert witnesses as routine—not in every case, randomly—have more regional hearings for the Court of Protection and more nominated local judges who could speed up that process so that this was something that happened regionally and your case was heard more quickly. Often these are people who may not have a lot of time, and these cases can take a long time, but similarly they can be heard very quickly if the need is urgent.

Although tribunals sound like a great idea—and I think I am mid-way to changing my mind on my view—if they are not resourced and if representation is not made freely available to people, that would be a huge burden for somebody to bear. If local authorities were suddenly expected to have to develop a local tribunal and resource it, it may result in something worse than what we currently have, and I would hate to advocate something that made things worse. Without a doubt, it needs to be speedier and cost less, but there are changes to the Court of Protection as it currently stands that could achieve that. We would not lose the expertise; some of these judges have built up such a fantastic body of expertise now that we really value. It would be a loss.

The Chairman: So, you are really saying that you would prefer satellite courts in local areas with the expertise of the judges of the Court of Protection, almost like the Court going on circuit.

Lorraine Currie: Yes, something along those lines could speed the process up, and the removal of experts could make that less expensive for local authorities.

Terry Dafter: There is a real body of evidence on this now, is there not?

Lord Swinfen: You mentioned experts giving evidence. Where do the experts come from? Are they just people doing your job in a different part of the country?

Lorraine Currie: I would not know how they get on to an expert list. I do not know that, but experts are generally people who, I believe, call themselves experts. Their expertise then comes because they have done this X times in the Court of Protection. They will be psychiatrists or psychologists who are therefore seen to have more expertise in the field, but there are some recent court decisions preferring the evidence of people who do this more day in, day out and possibly know the service user better.

The Chairman: Thank you very much indeed for a very interesting session.

Terry Dafter: Just for the record, could I just let you know that I am no longer Joint Chair of the ADASS Network since last week? I have had to take on other responsibilities within ADASS. I am a member of the network.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
The Chairman: Thank you very much.
Association of Public Authority Deputies – Written evidence

Overview and context

1. To what extent has the Mental Capacity Act 2005 (MCA) achieved its aims?

It is our considered view that the MCA 2005 has only partially achieved its aims due, we believe, in part due to a lack of clarity about the aims of the Act and as evidenced by the inconsistent application of the Act by the various public and third sector organisations.

The MCA 2005 has achieved some of its more specific aims in relation to the management of mentally incapacitated adults’ property and financial affairs by enabling Deputies (in our case Corporate Deputies) to make broader financial decisions than the previous Court of Protection appointed receiver.

Using the principles of best interest decision making to evidence the taking of decisions on behalf of P allows us to act quickly and with objectivity without restricting or delaying any decision making process.

2. Which areas of the Act, if any, require amendment; and how?

For many people working in the area of adult safeguarding clarity around what constitutes an offence under the Act would be received positively, especially in the area of financial abuse.

Across the country local authority staff working in the area of investigation of financial abuse find the perceived lack of response from some partner agencies regarding the evidence threshold for pursuing legal action against those who steal from, exploit or defraud vulnerable adults increasingly frustrating and consider that the Act in not being implemented to its fullest extent.

Whilst prosecutions appear to be increasingly successful in relation to s44 offences concerned with the provision of care too many times we hear that an Attorney using P’s income or assets for his own benefit (and often to the detriment of P) is not guilty of any offence when this is clearly not the case.

3. At the core of the MCA are its principles and definitions of capacity and best interests. Are these appropriate?

Yes, in the main. Greater clarity contained in guidance notes/information booklets regarding as assessment of incapacity in one area of decision making does not mean that P cannot make any decisions for himself related to the same area of decision making – lack of capacity to cook a meal does not mean that P cannot decide what he wants for breakfast, lunch and/or dinner

A toolkit of examples of questions to support the assessment of capacity in different areas of decision making would, I think, be beneficial to practitioners and increase their confidence in carrying out multiple assessments of capacity

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
4. Implementation

5. To what extent have the five principles of the MCA been implemented in frontline practice? What evidence is available to assess this? Is there a satisfactory balance between enablement and protection?

There is some evidence that the five principles of the MCA are being implemented by those working on the frontline – but there is also evidence that the implementation is inconsistent.

The evidence is available through consideration of individual case files and investigation of cases post-intervention – eg in cases where safeguarding referrals are received and there is retrospective back-tracking to establish the facts of the case.

Achieving the balance between enablement and protection can be challenging for frontline practitioners – especially where services are subject to multiple levels of scrutiny but there is also public interest in what actions staff have taken. Staff are conscious that often the demands of carers or other interested parties are not conducive to enabling P to live independently etc and they are quick to criticise frontline workers for not intervening appropriately.

6. How effective was the Government’s implementation plan? What measures were taken to ensure that professionals and families of those who lack capacity know about and act in accordance with the provisions of the MCA? Has it led to sustainable change?

Not very in relation to general public awareness – or it was “patchy” at its best. Few family members or carers seemed (still don’t seem) familiar with the provisions of the act and this can cause challenge when decisions about long term care etc have to be made.

That having been said figures quoted by the OPG would indicate that there is an increasing number of people executing LPA’s so the message must be getting through to some groups.

7. Is the Act widely known and understood by professionals required to implement it? How does this differ across different sectors, such as health, social care, banking and others?

Knowledge and understanding across professionals is varied and inconsistent. Key organisations that interface with vulnerable adults who may lack mental capacity in some areas of decision making appear to pay scant regard to the Mental Capacity Act when it comes to delivery of front line services – eg Department for Work and Pensions, Banking sector generally, health professionals and service providers who contract with customers even though their capacity to enter into a contract is questionable.

8. Is the Act widely known and understood by those who are directly affected by it and by their non-professional carers? To what extent does the Act provide

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protection and reassurance for informal carers? Has the right balance between
struck between protection of the carer and protection of the individual lacking
capacity?

Knowledge and understanding of the Act appears limited by those directly affected
by it or by their non-professional carers. There appears to be a lot of
misunderstanding about what informal carers can/can’t do on behalf of a vulnerable
or incapacitated adult which often leaves the informal carer vulnerable himself to
allegations of “wrong-doing.”

9. Has the Act ushered in the expected, or any, change in the culture of care?

For some vulnerable adults the implementation of the Act has meant an increased
involvement in their own care, with frontline staff embracing the principles of the
Act and taking more account of the feelings and wishes of the incapacitated adult.

10. Is there any evidence that the provisions of the MCA affect some groups
disproportionately? If so, what data exists to compare representation across
different socio-economic groups, Black and Minority Ethnic groups, and gender?

I am not aware of any data which would evidence this this – certainly many APAD
members support service users across different socio-economic groups, Black and
Minority Ethnic groups, different genders etc.

11. Decision making

12. Are those directly affected by the Act being enabled and supported to make
decisions for themselves to a greater or lesser extent than they would have been in
the past? Does the means by which the decision is made – ‘general authority’, Lasting
Power of Attorney, deputyship, Court of Protection – affect the quality of decision
making?

In some cases – progress has been slow and practice in relation to decision making
has had to be consistently challenged in an attempt to embed the principles and also
to encourage the execution of LPA’s.

13. What evidence is there that advance decisions to refuse treatment are being
made and followed?

I have no knowledge of this area

14. Has the MCA fostered appropriate involvement of carers and families in
decision-making?

In some cases – though there is still much work to be done to ensure that the views
of all appropriate carers are canvassed, too often professionals will “work”/liaise
with one member of the family, making little or no attempt to establish the wider
circle of interested parties
15. Has the role of the Independent Mental Capacity Advocate (IMCA) succeeded in providing a voice for clients and an additional safeguard against abuse and exploitation for those who have no-one to speak on their behalf?

In the main – though referrals to IMCA’s can still be restricted. Also whilst IMCA are sometimes involved in the Best Interest Decision making process in relation to decisions about long term care/changes of residence etc they are rarely involved in the decision making about who should support P with managing his finances if P has been assessed as lacking the mental capacity to manage his financial affairs himself though in practice it ought to be relatively easy to make both decisions at the same time if the IMCA has taken the opportunity to elicit P’s feelings and wishes about both areas of decision making during discussions with/visits to P.

16. Has the level of referrals to IMCAs met expectations? What are the reasons for the regional variations in the number of referrals?

Generally referrals numbers are not as expected in this area. The reasons for this are unclear – other than lack of understanding on behalf of professionals about when to involve an IMCA

17. Are IMCAs adequately resourced and skilled to assist in supported or substituted decision making for people lacking capacity?

Local experience of the IMCA service has been positive in the main

18. Deprivation of Liberty Safeguards

19. Are the safeguards in the Deprivation of Liberty Safeguards (DoLS) adequate?

Insufficient knowledge of DOLS to formulate an evidenced based response though experience of individual cases would indicate that the DoLS are providing an element

20. Are the processes for authorisation, review and challenge of DoLS sufficiently clear, accessible and timely?

21. The Court of Protection and the Office of the Public Guardian

Are the Court of Protection and the Office of the Public Guardian sufficiently understood and accessible to all? Are they operating effectively and successfully?

There is still some confusion about the roles of the two organisations and some “mystic” about them as well as a number of myths regarding the costs of applying to the Court of Protection and the ability of the OPG to take positive action against those who financially abuse vulnerable adults.

Whilst there is a wealth of information about both the Court of Protection and the OPG on the internet not everyone has access to this or is confident enough to trawl through the different websites and pages of an organisation’s website to extract the information that they need.

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With regard to the Deputyship application process many staff working in this area find it frustrating that there is little information available in easy read format when the very fact that any application to the Court of Protection is being made indicates that P’s level of understanding may be compromised. Forms such as the COP14 and annual report should at the very least be converted into easy read format so that these can be more easily shared with and, hopefully, understood by P.

Many concerns have been raised locally, regionally and nationally about the failure of the OPG to engage with local safeguarding teams and procedures.

Although OPG procedures state that local safeguarding teams will be alerted to concerns about a vulnerable adult living in that Council’s administrative area where the OPG has been asked to investigate allegations of financial abuse I and many of my colleagues can find no trace of OPG staff being the referral agent/alerner.

Other concerns have been raised regarding the time taken to process applications to the Court – experience is mixed across the country with some local authorities receiving Orders within 6-8 weeks where other councils report waiting times of 6 months plus for Orders to be granted.

For local authorities a significant issue is the payment of fees which are disproportionate with those paid to “professional” deputies – despite the fact that corporate deputies are taking on very complex cases, many which solicitors in private practice would refuse to take on.

The current fee structure is not fit for purpose and there appears to be no mechanism for addressing this issue quickly or effectively.

22. What has been the impact of the introduction of Lasting Powers of Attorney (LPA), especially with regard to decision making on matters of personal care and welfare?

Little evidence of these – but where they do understanding of their impact on decision making can appear mixed.

Few LPA’s for Health and Welfare appear to have been “lodged” with appropriate bodies so professionals make decisions ignorant of the fact that the Attorney should be the decision maker.

Professional bodies do not have the resources to check whether there is a registered LPA for Health and Welfare in all cases – an automatic system of transferring information about LPA’s registered with the OPG (at the point of registration) to organisations such as the NHS and local authorities would ensure that the data is held centrally and accessible to those organisations’ staff working with P and ensure then that P’s wishes about who should make decisions about his health and welfare would be complied with.

23. What concerns, if any, are there regarding the costs associated with registering an LPA, or with making an application to the Court of Protection?

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Evidence obtained locally indicates that the registration fee for LPA does not put people off registering the instrument, although it has been suggested that it may act as a deterrent for those wishing to financially abuse a vulnerable adult.

The fees charged by solicitors for executing LPA’s appears to vary considerably not just nationally but locally as well – this can sometimes confuse P and family members who believe that the higher fees charged means that an application is being made to the Court of Protection.

Again fees charged by solicitors for applications to the Court of Protection on behalf of lay deputies appear to vary significantly and can act as a deterrent for family members to make the application over the local authority – although councils should only make applications as a last resort.

Local authorities make significant numbers of applications to the Court of Protection and the difference in fee levels between councils and private solicitors or other third sector organisations is disproportionate, especially given the Court’s view that local authorities cannot refer cases for a Panel Deputy due to the complexity of a case or due to caseload numbers.

Increasingly local authorities are receiving requests to apply to the Court of Protection in order to obtain information relating to safeguarding investigations and where there is little evidence of assets – experience shows that solicitors are reluctant to take on cases where:

a) the value of assets are unknown
b) where assets are minimal,
c) where there is dispute amongst family members or
c) where the case is complex

24. Is legal aid available and sufficient? What impact will the recent and proposed reforms to legal aid have?

Unsure at this time

25. Regulation

26. Is the role of the Care Quality Commission in inspecting on the MCA standards adequate and appropriate? Is there a case for additional powers?

I am uncertain as to how CQC fit inspection of MCA standards into their monitoring framework or toolkit but would suggest that CQC should inspect financial management at care homes and Care Providers of Home care and be able to recommend alternative management where a provider is failing.

27. Should other regulatory bodies, such as health and social care professional regulators, be acting in this area?

Health and social care regulatory bodies should build MCA monitoring into their inspection frameworks and local authorities would welcome other regulators.

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building audit toolkits into their system to consider the management of finances of adults at risk in a care home or in their own homes.

Other legislation

1. How well is the relationship with the mental health system and legislation understood in practice?

Understanding is mixed – mental health professionals have worked so long with the MHA that it appears they have struggled to understand the relationship between the two pieces of legislation more than those working outside of the mental health field

2. Devolved administrations and international context

3. Does the implementation of the Mental Capacity Act differ significantly in Wales?

Uncertain but feedback would suggest that the experience of staff working for Welsh local authorities is pretty similar to that reflected already in this response

4. What lessons, if any, can be learnt from the approaches taken to mental capacity legislation in Scotland and Northern Ireland, or in other jurisdictions?

Insufficient knowledge of legislation in other jurisdictions to be able to answer this point

5. Is the MCA compliant with the United Nations Convention on the Rights of Persons with Disability (CRPD)? Are there lessons that can be learnt from the CRPD for the successful implementation of the MCA?

Uncertain

I trust that the above is acceptable and of some use to you.

Please accept this submission on behalf of APAD and feel free to contact me if you require clarification on any of the points made or any further information.

30 August 2013
I wish to address the submission document’s question 24 - How well is the relationship with the mental health system and legislation understood in practice?

My experience of lecturing on the relationship between the Mental Health Act 1983 and the Mental Capacity Act 2005, and in particular the powers and scope of Guardianship in relation to the Mental Capacity Act, is that the relationship is not easy to identify or describe.

My experience of use of Guardianship when I was an Approved Social Worker is that in the past it provided a very helpful framework of care for vulnerable people, but its use may now be overlooked because the Mental Capacity Act appears to practitioners to offer a less formal process to achieve the same result, usually around the management of someone with a mental disorder in a care home.

My view is that there are number of key features of Guardianship under the Mental Health Act that can provide safeguards for patients as well as allowing for effective care, and perhaps guidance should be issued specifically on when and how to use Guardianship. I wonder how much Guardianship now features in the continued professional development of mental health and care staff.

To assist me in delivering lectures on the topic of Guardianship to trainee Approved Mental Health Professionals and Deprivation of Liberty Safeguards Best Interests assessors I compiled a list of positive features of Guardianship and I list these here:

- The Mental Health Act and Guardianship definition of mental disorder is narrower than that for the Mental Capacity Act
- The philosophy and purpose of the Guardianship under the Act is about the welfare of the person and of others, not just the best interests of the person
- There is a structure of completing recommendations, applications, scrutiny and receipt of forms and a means of appeal to an independent tribunal.
- The person’s nearest relative has a number of powers including right of discharge
- Guardianship can apply to people who and who do have capacity as well as those who lack capacity, to make decisions about their care.
- Patients under Guardianship must be visited and there is a strict timetable of visiting, and for writing reports prior to renewal of Guardianship Orders
- Amendments to the Mental Health Act now mean there is legal authority to convey someone to a care home
- The nature of Guardianship where the Local Authority is the Guardian means that one person (a LA representative,) can take the lead in the decision making process and co-ordinating care with the legal backing of the Mental Health Act

My views on this question are as follows:

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David Beckingham (University of Cumbria) – Written evidence

- That up-to-date guidance on the use of Guardianship should be issued in respect of when and how it should be used, and how it relates to other legislation (particularly in the light of recent case law)
- That there should be encouragement of ongoing training and professional development around the use of Guardianship

I am an Honorary Lecturer with the University of Cumbria. I am a registered social worker with the Health Care Professions Council. I am self-employed, and I write this submission in a personal and individual capacity.

30 August 2013
Overview and context

1. To what extent has the Mental Capacity Act 2005 (MCA) achieved its aims?

From my point of view, as a social worker in safeguarding adults, an AMHP and a BIA I think the MCA has gone some way to ensure that individuals rights are considered where they lack mental capacity.

2. Which areas of the Act, if any, require amendment; and how?

3. At the core of the MCA are its principles and definitions of capacity and best interests. Are these appropriate?

Implementation

4. To what extent have the five principles of the MCA been implemented in frontline practice? What evidence is available to assess this? Is there a satisfactory balance between enablement and protection?

5. How effective was the Government’s implementation plan? What measures were taken to ensure that professionals and families of those who lack capacity know about and act in accordance with the provisions of the MCA? Has it led to sustainable change?

I really believe that awareness of the MCA is limited across both professionals and the general public. Initially, there was some ring-fenced funding for local authorities to raise the profile of DoLS and as a result the MCA, this has now been removed. Local authorities have insufficient funds to train the community and it is evident to me that the MCA is not used effectively in practice.

I think there should be an MCA Lead in local authorities, not only for DoLS. Especially in Adult Care Management practitioners may only have NVQ qualifications and no professional foundation yet they are considering some major decisions regarding customers in their care. Increasingly, there are complex cases, involving safeguarding issues, where mental capacity is central there needs to be acknowledgement of the need to have experienced professionals to oversee these and ensure staff and the local authority are trained and using the MCA – this is separate and in addition to the Deprivation of Liberty Safeguards. I also think this should be a social worker role too many authorities have moved to non-professionally qualified staff (who then climb the management ladder) and as they do not have the level of training and understanding that social workers have I think the use of the mca and other legislation is not really considered. The knowledge and skills of social workers needs to be acknowledged by the government (as it is by the courts).

6. Is the Act widely known and understood by professionals required to implement it? How does this differ across different sectors, such as health, social care, banking and others?

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
I have found that whilst professionals may have some basic training the manner in which it is implemented varies. I know of psychiatrists who hold mental capacity assessment meetings, where the customer is brought along to be assessed, I think this is oppressive and not in the spirit of the MCA. I have noticed that mental health CPA care plans do not include reference to MCA and doctors often use the term insight instead of MCA. In general hospitals there is limited adherence to MCA but I have seen some improvement, not so much with DoLS though.

7. Is the Act widely known and understood by those who are directly affected by it and by their non-professional carers? To what extent does the Act provide protection and reassurance for informal carers? Has the right balance between struck between protection of the carer and protection of the individual lacking capacity?

This is quite difficult when I am involved with safeguarding investigations where the alleged perpetrator is a carer. Safeguarding procedures need to have a firm legislative framework that dovetails with MCA.

8. Has the Act ushered in the expected, or any, change in the culture of care?

I would say not sufficiently, recording of mc assessments is poor across care homes and hospitals and recording of Best Interests Decisions. Some confusion about who the Decision Maker is.

9. Is there any evidence that the provisions of the MCA affect some groups disproportionately? If so, what data exists to compare representation across different socio-economic groups, Black and Minority Ethnic groups, and gender?

Decision making

10. Are those directly affected by the Act being enabled and supported to make decisions for themselves to a greater or lesser extent than they would have been in the past? Does the means by which the decision is made – ‘general authority’, Lasting Power of Attorney, deputyship, Court of Protection – affect the quality of decision making?

11. What evidence is there that advance decisions to refuse treatment are being made and followed?

12. Has the MCA fostered appropriate involvement of carers and families in decision-making?

13. Has the role of the Independent Mental Capacity Advocate (IMCA) succeeded in providing a voice for clients and an additional safeguard against abuse and exploitation for those who have no-one to speak on their behalf?

No, I do not think so. I act as Case Lead in safeguarding investigations and try to liaise with the IMCA service, it has not been my experience that they will speak up what they seem to

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do is relate in parrot style the MCA. I have found the IMCA services put obstacles in the way of becoming involved for example, demanding a mental capacity assessment before becoming involved in safeguarding cases whereas where it is believe a person lacks mental capacity and there is concern around abuse they should be involved at the earliest opportunity.

They still seem confused about the need to be instructed by the customer and repeat exactly what they say rather than a more balanced approach.

14. Has the level of referrals to IMCAs met expectations? What are the reasons for the regional variations in the number of referrals?

I think there has been a lack of referrals to IMCA’s in our area as there is not a good working relationship. The service has set itself up against the local authority and seem to put obstacles in the way; arguing little points around process rather than putting the customer first.

Why go through the hurdles to engage an IMCA when there seems to be no benefit to anyone?

They will not respond to urgent situations.

15. Are IMCAs adequately resourced and skilled to assist in supported or substituted decision making for people lacking capacity?

I firmly believe there should be regulatory body to monitor the ability and conduct of IMCA’s (and other advocates). There should be a minimum standard for their practice. Whilst I welcome the Expert by Experience of advocates this should not get in the way of acting objectively and in a professional manner.

Deprivation of Liberty Safeguards

16. Are the safeguards in the Deprivation of Liberty Safeguards (DoLS) adequate?

17. Are the processes for authorisation, review and challenge of DoLS sufficiently clear, accessible and timely?

The Court of Protection and the Office of the Public Guardian

18. Are the Court of Protection and the Office of the Public Guardian sufficiently understood and accessible to all? Are they operating effectively and successfully?

I think access to the CoP is very difficult, the number of forms, the time delay, the cost etc make it inaccessible to most people.

I was involved in a recent case regarding deprivation of liberty and think the CoP could have paid more regard to the safeguarding/SOVA issues raised and the responsibilities of local authorities in this rather than wholly the MCA.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Kate Beynon PSW/ BIA/ AMHP (Safeguarding Adults Team, Northamptonshire County Council) – Written evidence

My experiences of the judges in the CoP is that they are very human, knowledgeable and caring people who put the individual concerned at the centre of the case. The judge took the person into his chambers to talk to him individually and prepared a letter for the person to explain the outcome, this was a lovely touch.

I found the role of the Official Solicitor to be confusing. They seemed to be acting for the mother of the person (who did not have legal representation) rather than the person and the judge had to remind them who they were there to represent. The OS asked for significant amounts of information at short notice and seemed to be totally against the local authority having access to the CoP threatening costs at every step of the way when, in the end, the judge considered the local authority case to be unequivocal. They do not seem to keep in contact with the person.

We were requested to provide various reports for example; best interests balance sheets but received no templates etc. There should be a library of templates for reports for use at CoP.

The High Courts are inaccessible to a lot of people who are unable or cannot afford to travel to the locations. Why can we not have local Tribunals similar to Mental Health Tribunals? They both consider deprivations of people’s liberty but under different legislation. The MHRT’s are held in a more informal setting, they are set up speedily and can make decisions at a local level, and this can be challenged through due process if necessary. This would enable people to engage with the court process and avoid long delays and expense. The most serious cases – for example; life sustaining treatment could still be heard in the High Court.

19. What has been the impact of the introduction of Lasting Powers of Attorney (LPA), especially with regard to decision making on matters of personal care and welfare?

20. What concerns, if any, are there regarding the costs associated with registering an LPA, or with making an application to the Court of Protection?

The costs exclude people from making applications to Court, it is also very hard to understand. A lot of people still do not use or understand the internet. How can a person who lacks mental capacity have their case heard in court, who would identify this and take it forward – it is not always appropriate for the local authority to do this, or they may not be aware.

21. Is legal aid available and sufficient? What impact will the recent and proposed reforms to legal aid have?

I was involved in a recent CoP case and am very worried that one of the parties was not able to access legal aid, she was in debt and could not afford repayments and yet we were removing her adult son from her care.

Regulation

22. Is the role of the Care Quality Commission in inspecting on the MCA standards adequate and appropriate? Is there a case for additional powers?

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
I work for the local county council and also as a mental health act commissioner, it is my experience that the CQC compliance inspectors do not understand MCA and DoLs. The training is insufficient and I agree the CQC needs to employ specialists in various areas rather than training up people to become compliance inspectors who have experience in fire fighting or IT. They have recently advertised for bank inspectors but made no reference to the ‘army’ of specialists espoused by their new chief executive, until they employ people of a high professional standard they will not adequately be able to monitor compliance with MCA and DoLS.

23. Should other regulatory bodies, such as health and social care professional regulators, be acting in this area?

I do not think health fully understand this area yet, social care regulators with social work training would be more suitable.

Other legislation

24. How well is the relationship with the mental health system and legislation understood in practice?

I undertake both the AMHP and BIA role and I still find the two quite hard to dovetail together. The knowledge and experience of mental health workers from health is scant in relation to the MCA. I went out to a hospital some time ago (that has now closed due to wilful neglect) and found no acknowledgement of consideration or use of either legal framework, this was not picked up by any commissioning authority (PCT’s at the time, now CCG’s who still do not understand MCA), local health services, local authority or CQC. All those agencies were unable to identify lack of adherence to legislation and more importantly, ongoing abuse of the adults in their care.

I have found, especially in older people’s mental health wards, there is little consideration of mental capacity. People who refuse food, drink and medication have this recorded on their notes but there is a lack of consideration of use of the MCA, the person then becomes dehydrated and ill and the doctors then consider the use of the MHA.

There is confusion about the role of Decision Maker, with mental health hospitals believing this is the responsibility of the Consultant – not a regular and dynamic process with different professionals being responsible.

I know of Mental Health Act Administrators who also act as Mental Capacity Leads, they have no practice experience and the hospital trust has a lot of mental health detentions and very few DoLS in place (perhaps 1). This is down to lack of knowledge and practice experience. In health, safeguarding leads – who are nurses – often attend and manage MCA and DoLS training, when they do not themselves understand the legislation.

Devolved administrations and international context

25. Does the implementation of the Mental Capacity Act differ significantly in Wales?

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
26. What lessons, if any, can be learnt from the approaches taken to mental capacity legislation in Scotland and Northern Ireland, or in other jurisdictions?

27. Is the MCA compliant with the United Nations Convention on the Rights of Persons with Disability (CRPD)? Are there lessons that can be learnt from the CRPD for the successful implementation of the MCA?

3 September 2013
In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
1. **Background**

1.1. This submission is presented in my personal capacity.

1.2. The submission is in the form of an amended commentary on the matter of Ruth Minna Boff – [Court of Protection Decision No 12338771](#). I have been involved in this matter as the donee of an LPA from my wife. Getting this registered was a saga.

1.3. The Decision followed the first contested challenge to a proposed severance of terms from an LPA.

1.4. The original commentary was sent to Senior Judge Lush of the Court of Protection, who informed us of the existence of your enquiry and suggested that I send my comments to you.

1.5. From the commentary, various features of the proceedings will be evident as will my view of the proceedings.

1.6. At paragraph 7.11 I had suggested that an enquiry into the operation of the Mental Capacity Act was advisable. I am glad that this enquiry was already underway.

2. **The Procedure**

2.1. Paragraph 18 states that “this is the first time that either a donor or an attorney has ever formally objected to an application by the OPG to sever an ineffective provision from an LPA.”

2.2. Perhaps this explains the somewhat poor handling of the formalities of the action.

2.3. It should be noted that that:-

   - The donor was never served with the directions order dated 14th June 2013;
   - The directions order of 14th June 2013 appears to be in breach of Rule 84(4) Court of Protection Rules 2007 which requires that the notice of hearing “state whether the hearing is for disposing of the matter or for directions” - no such statement was made in the directions order;
   - The donor’s papers that were submitted by hand to the COP 28th June 2013 were submitted in response to the copy of the application sent to the donor by the COP; and
   - These papers had not reached the judge by the hearing 1st August 2013 and the judge had to be supplied a copy at the hearing by the applicant.

2.4. It is to be hoped that the next case is handled in a more appropriate manner.

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3. **The heroic expansion of Pepper v Hart**

3.1. The case turns on whether the word “original” should have appeared in the legislation or should be read into the legislation.

3.2. Paragraphs 22-25 of the decision seek to determine the intent of the Law Commission preceding the enactment of the Mental Capacity Act 2005.

3.3. Paragraph 22 states that in 1983 the Law Commission was against any form of replacement of attorneys.

3.4. Paragraph 23 states that in 1995 the Law Commission had changed its mind on successive appointments and then considered them to be a good thing.

3.5. Paragraph 24 states that the draft Mental Incapacity Bill had a clause identical in substance to that passed in the Mental Capacity Act 2005 but that “almost certainly by accident rather than by design, it did not specifically refer to ‘the original donee.’”

3.6. Paragraph 25 states that “I imagine that the omission arose because the person who drafted the Bill simply gathered together all the recommendations that the Law Commission had made in its report.”

3.7. Paragraph 45 states that “What is striking is the complete absence of any reference, anywhere, to the possibility that a replacement attorney can replace a replacement attorney....”

3.8. Paragraph 50 states that “The appointment of successive attorneys creates complexities that were never properly addressed by either the Law Commission in its report number 231 on Mental Incapacity (1995) or by the Parliamentary draftsman in the Mental Capacity Act 2005”.

3.9. Pepper & Hart was first referred to at the hearing. Paragraph 43 of the decision refers to Pepper & Hart as giving authority to look to the legislative history to seek the intent of Parliament and quotes Lord Griffiths. I quote Lord Browne-Wilkinson who read the lead decision:-

> “Even in such cases references in court to Parliamentary material should only be permitted where such material clearly discloses the mischief aimed at or the legislative intention lying behind the ambiguous or obscure words.”

3.10. The decision clearly acknowledges the fact that the Law Commission did not consider the issue of replacement of a replacement attorney and did not discuss any problems with this: accordingly, no such mischief is disclosed.

3.11. Rather than looking to any mischief clearly disclosed in the Law Commission report, the decision speculates on why the Law Commission made no mention of any problems: this despite the clear reversal in intent between the first and second Law Commission reports.

3.12. The decision therefore extends Pepper v Hart way beyond its original scope and considers that laws should be interpreted:-

- not in accordance with the language used in the statute;
- not in accordance with the language proposed by the Law Commission;
- not to deal with any issue addressed or commented on by the Law Commission;

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but to deal with complexities that the judge thinks the Law Commission should have had the wit to comment on. This is clearly inappropriate and places legal interpretation at the whim of the judge.

4. The use of forms as law

4.1. Paragraphs 32-40 seek to place the prescribed forms in the position of being legislation.

4.2. Paragraph 1(3) to Schedule 1 of the MCA is quoted in part in the decision as indicating that the Lord Chancellor may make regulations. This is not denied.

4.3. However Schedule 1 relates to “Formalities” and Paragraph 1(1) clearly states that:

\[(1) \text{An instrument is not made in accordance with this Schedule unless—}\]

\[(a) \text{it is in the prescribed form,}\]

\[(b) \text{it complies with paragraph 2, and}\]

\[(c) \text{any prescribed requirements in connection with its execution are satisfied.}\]

4.4. It should be noted that paragraph 3 of Schedule 1 states that:

If an instrument differs in an immaterial respect in form or mode of expression from the prescribed form, it is to be treated by the Public Guardian as sufficient in point of form and expression.

4.5. It is thus evident that the regulations may bite on form, but not on substance. Whether a replacement attorney may be replaced by another attorney is a matter of substance not form.


4.7. The Rules indeed prescribe a form; but do not provide any substantive requirement concerning replacement of replacement attorneys.

4.8. Instead the decision makes reference to the content of the form. Paragraphs 35-37 of the decision seek to elevate explanatory notes and tick boxes to the level of legislation; and to elevate statements read by the attorney, to conditions binding on the donor.

4.9. It should be noted in passing, that the attorney statement mentioned in paragraph 39 is not as originally passed. The language of the statement was changed by SI2009/1884 – perhaps in response to re Baldwin – a decision that was a consent order as mentioned in paragraph 41.

4.10. The wording has changed from:
Mr and Mrs Boff – Written evidence

“If an original attorney’s appointment is terminated, I will replace the original attorney, if I am still eligible to act as an attorney. I understand I do not have the authority to act under this LPA until the relevant attorney’s appointment is terminated."

to

“If an original attorney’s appointment is terminated, I will replace the original attorney, if I am still eligible to act as an attorney. I have the authority to act under this lasting power of attorney only after an original attorney’s appointment is terminated and I have notified the Public Guardian of the event.”

4.11. It should be noted that the explanatory note to the SI contain no explanation for this change of wording. Legislation by stealth is not a practice that is encouraged.

4.12. It is clear that the prescribed form is simply intended to ensure that the necessary information is provided to enable registration, and does not of itself create any new substantive requirement.

4.13. In summary, placing the form on the level of substantive legislation means that:-

- The Law Commission did not mention the situation of an LPA having provision concerning replacement of a replacement attorney
- Parliament in enacting the MCA did not mention the situation of an LPA having provision concerning replacement of a replacement attorney
- Parliament in passing the original Rules did not mention the situation of an LPA having provision concerning replacement of a replacement attorney
- Parliament in replacing the original Rules did not mention to the donor in the form the situation of an LPA having provision concerning replacement of a replacement attorney; but only mentioned it without corresponding explanation in the form executed by the attorney (presupposing that Parliament even noticed the change in wording).

4.14. This is no way to make legislation and is, frankly, incredible.

5. The OPG’s Guidance

5.1. Reference to the OPG Guidance in the decision is inappropriate. The OPG’s opinion is not, and cannot, be law. If statutory bodies can make law by issuing guidance, what function does Parliament have?

6. Evasion of legislative intent

6.1. Paragraph 46 reaches a decision in effect interpreting the legislative history to find that Parliament did not intend that a replacement attorney could be replaced by another attorney.

6.2. Paragraph 48 states that the result desired may be achieved by a different route.

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6.3. A decision telling the recipient how to avoid legislative intent appears inappropriate. It would be interesting if, say, a tax tribunal acted in this manner. This decision is inconsistent.

7. Further observations

7.1. It is evident that all concerned at the OPG and COP are well meaning. However the practice and administration of the MCA by the OPG and COP appears deficient, and the law may require clarification if the OPG and COP are to be able to meet Parliamentary intent.

7.2. It appears to me that Paragraph 51 of the decision raises many practical problems that appear to be inherent in the present system, at least as interpreted by the OPG and COP. In particular I note that:-

(1) Points 1 and 2 could be dealt with administratively, for example by simply sending a copy of the LPA to each attorney or replacement attorney.

(2) Point 3 could be dealt with appropriately by appropriate language on the form indicating whether replacement of a joint attorney is intended to replace all, or just one of those attorneys. This would remove any ambiguity.

(3) The view expressed in Point 4 on replacement of joint attorneys appears inconsistent with both how the general public would understand the situation; and with a plain reading of the forms. Box 4 states how attorneys should act and gives no warning that a replacement of one is effectively replacement of all – even though this is how this appears to be interpreted.

7.3. So it appears that the problems largely lie in administration of what is a mandatory requirement – that replacement should be permitted.

7.4. I note from Paragraph 52 of the decision that “These are some of the reasons why the appointment of successive attorneys was traditionally regarded as a no go area”. Parliament did not fear to go here, and expressly allowed replacement of attorneys.

7.5. It appears to me that the OPG and COP are insistent on ignoring the language of the law [which is expressed as “An Act to make new provision relating to persons who lack capacity...”] and are trying hard to make the law look as “traditional” as possible by adopting a minimalist approach to any changes introduced. The law should be interpreted in a way that might make it work as intended, not in a way that preserves the comfort level of lawyers.

7.6. It is further noted that the entire scheme appears poorly thought through.

7.7. As referred to in the hearing, the age profile of persons who are registering powers of attorney would indicate that they tend to be those who are approaching lack of capacity. This means that decisions are taken in a hurry, and any problems in administration take place at a time when donors or their attorneys are least able to consider and cope with them. If there are any problems, donors are hence not inclined to challenge an OPG determination as it would introduce a delay at a critical time. This, perhaps, is why this case is the first to reach the court, as my wife is not in a hurry, and a long way from losing capacity.

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7.8. In contrast, anyone who acts prudently by making an LPA well in advance is faced with either:-

- registering at a time when they are capable [in which case the default position of the forms - that the LPA takes effect on registration immediately unless indicated otherwise by the donor - seems inappropriate]; or
- only seeking to register when the LPA is needed, in which case any failure of form or substance may make the LPA ineffective.

7.9. It appears to me that although the law is expressed in reasonably clear terms, the administration of the law makes it unclear and impenetrable, and guaranteed in many cases to introduce results contrary to the wishes and expectations of the donor.

7.10. I am glad that in paragraph 42 the decision recognises that my wife is intelligent. If even such an intelligent person can be misled, then it is evidence that the forms and practice are inadequate. The majority of persons executing an LPA are not of her calibre. I fear that many of those entering into LPAs are not in a position to fully understand all the implications of the documents they are signing, either through lack of capacity, or due to the impenetrable and unadvertised interpretations placed on the law. The law and the forms need to be as clear and complete as possible so that the donor has no doubt. If there is doubt, then this casts doubt on the value and validity of both the LPA and the entire system.

7.11. I suggest that a thorough review of:-

- what the law was intended to do;
- how the law is being applied;
- the administrative regime for effecting the law’s intent; and
- the forms and guidance provided to donors and attorneys.

would be a good idea. Further, I suggest that this may be urgent. From the present experience I suggest that there are many registered and unregistered powers that do not reflect the donor’s intent.

7.12. I still believe that having an LPA is a good idea. Even if the administration of registering an LPA is problematic, registering an LPA at least minimises the chances that a person’s substantive affairs would be in the control of the OPG or COP. I am not left in confidence that substantive matters would be handled well in that event.

8. A practical matter

8.1. As will be evident, I consider the decision ill-founded in law. The reason an appeal is not being filed is simply cost. It is more effective for my wife to produce a second power as suggested in the decision, than to appeal this decision.

10 October 2013

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Derek Boothby AMHP/ BIA – Written evidence

This is my personal submission to the House of Lords Select Committee on the Mental Capacity Act. I am a practicing AMHP and BIA and the Mental Health training coordinator for Barnsley MBC, I train on both BIA and AMHP masters level training at local Universities, I also provide in house training to BMBC staff, our colleagues in the private sector and via our local CCG to hospital staff, GP's and Dentists etc , I have also provided some limited training to South Yorkshire Police and the probation service.

I have not attempted to answer all of the points

To what extent has the Mental Capacity Act 2005 (MCA) achieved its aims?

The Mental Capacity Act does provide a coherent framework for the care of those adults that may lack capacity in some regard, it does provide clarity for both carers and family, and does promote the welfare of those who lack capacity in some regard, and puts such people at the centre of decision making, it reinforces best interest principles and how this relates to capacity.

Which areas of the Act, if any, require amendment; and how?

In broad terms the act is well written and understandable, especially as this is supported by the code of practice, however the code needs to be updated to maintain its relevance, and this will need to be an ongoing process.

At the core of the MCA are its principles and definitions of capacity and best interests. Are these appropriate?

The core principles and the 2 stage of Capacity contained in the Act are well written and if applied, provide the basis for consistent decision making and care, for those who lack capacity in some regard. However some of the principles need more explanation than others, for example principle 3, as we live an increasingly litigious world staff are often loathe to allow people in their care to take risks, or make bad decisions for fear that they will be blamed in some way, some staff have said that they fear losing their job, so in order to protect themselves they conflate risk taking with lacking capacity and prevent people from making bad decisions, clearly this is for the benefit of the staff involved rather than (P)

To what extent have the five principles of the MCA been implemented in frontline practice? What evidence is available to assess this? Is there a satisfactory balance between enablement and protection?

The implementation of the core principles, has been patchy to say the least, where time effort and money has been expended there is a basic level of understanding, although custom and practice seem to have more relevance and meaning to staff, especially health colleagues who often think that good intentions and good care in order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
mean that they some how can override the principles. Where little training has been
done the core principles are ignored and are seen as having little relevance to
practice.

**How effective was the Government’s implementation plan? What measures were taken to ensure that professionals and families of those who lack capacity know about and act in accordance with the provisions of the MCA? Has it led to sustainable change?**

Was there an implementation plan proposed by Government? It appears that the
legislation has never been launched properly, there is little evidence that families in
particular have much knowledge of this legislation, there has been very little in the
way of public information, what little there has been, has been via the press and is
often negative in its interpretation.

There is a particular difficulty with Children’s services who fail to prepare the carers
of young adults for transition into the Adult care world, so a parent of a 15 year old
with a disability makes decisions until the Childs 16th birthday when they can be
marginalised and seen as peripheral to services.

Any sustainable change that has been made is as a result of the efforts of individual
authorities or regions rather than by any Government actions, who as a cost cutting
exercise in the ‘bonfire of the quangos’ did away with DOH national and regional
leads.

**Is the Act widely known and understood by professionals required to implement it? How does this differ across different sectors, such as health, social care, banking and others?**

There is a wide variation in the understanding of professionals, LSSA have the best
understanding especially Adult Services, for whom this has become the most
important piece of legislation, health colleagues are less familiar, Doctors generally
believe that they know how to assess capacity (erroneously in my opinion) and other
health staff are preoccupied with the notion of providing good but very paternalistic
care in which they’ know best’. Much work needs to be done in this area.

Outside of ‘caring’ agencies there is very little understanding from other agencies,
who fail to see the relevance for them, preferring to adhere to their own rules and
codes of conduct.

**Is the Act widely known and understood by those who are directly affected by it and by their non-professional carers? To what extent does the Act provide protection and reassurance for informal carers? Has the right balance between struck between protection of the carer and protection of the individual lacking capacity?**

There is little evidence to suggest that the act is well known and understood by both
carers and those affected by it.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Carers often feel that they should have the final say about their family member and find it hard to comprehend that Best interests may not necessarily chime with their wishes and feelings, likewise a capacity assessment may not harmonise with the families view of loved ones capacity.

At these times families need a 'crash course in MCA' and are often left feeling marginalised and ignored.

**Has the Act ushered in the expected, or any, change in the culture of care?**

The act has been successful in respect of those 'in the know' and even if not fully understood or implemented is starting to affect front line practice, the language of capacity and best interest is beginning to become more common and this in turn is definitely focusing attention on the act.

**Are the safeguards in the Deprivation of Liberty Safeguards (DoLS) adequate? Are the processes for authorisation, review and challenge of DoLS sufficiently clear, accessible and timely?**

The court 'deprivation' was unfortunate as this had negative connotations for managing authorities from the outset. However if properly implemented the safeguards do offer protection to those in need and provide a legal way to deprive (P) of his liberty that is Art 5 compliant.

The paperwork involved in an authorisation is overly complex and repetitive, this in itself can deter some managing authorities from making an application, however with some effort this can be overcome, the processes involved in review and challenge are, however, less well understood and their is a false belief that once an authorisation is given 'that's it', and no thought given to Art (5)4 compliance.

**Are the Court of Protection and the Office of the Public Guardian sufficiently understood and accessible to all? Are they operating effectively and successfully?**

The Court of Protection, in my experience offers a superb service, and as stated before, the course offer a Rolls Royce service, for those who can use it, but unfortunately has a Rolls Royce price tag to go with it. This can create, in my experience, some reluctance on the part of budget holders in Supervisory Bodies, from making early applications to the court, on the grounds of cost.

It would be massively beneficial to have a Tribunal system similar to that which operates in respect of the Mental Health act, this would ensure, speedier and easier access to the court system the Court of Protection then being reserved for those more serious cases, or those referred upwards from the Tribunal.

**Is the role of the Care Quality Commission in inspecting on the MCA standards adequate and appropriate? Is there a case for additional powers?**

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I have been involved locally, training CQC inspectors in this area, and it is fair to say that they are 'catching up'. Their understanding of the legislation needs to be at a sufficient level to be able to challenge any bad practice they encounter, and this is a 'big ask' especially as they have so much information and legislation to assimilate and understand. There is clearly a role for a more specialist inspection system to concentrate solely on this vital area.

**How well is the relationship with the mental health system and legislation understood in practice?**

The Mental Health act is well embedded and understood in comparison to the Mental Capacity act, the interface issues, challenge even the most astute and knowledgeable, the impenetrable nature of the schedules, relating to the MCA do not help in this respect, any legal challenge in this area, seems to add to the confusion rather than helping it.

In practice (P) can sometimes fall in the gap between the legislations thus being denied the Art 5 protections. There are huge areas of concern around the de facto detention of patients without capacity on mental health wards for example, it is in areas such as this that the interface issues become more problematic.

Some clarification in the code of practice would help in this area, as would a rewrite of the Mental Capacity act, to address this

28 August 2013

Submission to be found under Victoria Butler-Cole.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Dr Geraldine Boyle (School of Social and International Studies, University of Bradford) – Written evidence

My submission is informed by a recent study I led into decision-making by people with dementia and their spouses, funded by the ESRC (Boyle and Warren, 2013). As the research focused on people with dementia living at home, it addresses a key gap in current knowledge in relation to decision-making capacity in domestic contexts. Although the research related to spouses, the findings can be applied to carers more generally. The project website is as follows:

http://www.applied-social-research.brad.ac.uk/current-projects/decision-making-by-people-with-dementia/#d.en.81268

I was also involved in a recent study of best interests decision-making (BIDS) by health, social care and legal professionals on behalf of people lacking capacity (funded by the Dept. of Health), led by Dr. Val Williams at the University of Bristol. The BIDS project publications can be accessed from the same website:

http://www.applied-social-research.brad.ac.uk/publications/families-personal-lives-social-care-publications/#d.en.83798

My submission addresses key questions set out in the call for evidence, as follows:

1. The MCA has been important in providing a legislative framework which aims to balance empowerment and protection. The ongoing challenge relates to ensuring this balance is appropriately maintained in practice.

4. In relation to the principles of the Act, whilst carers often seek to encourage and facilitate the decision-making capacity of people with dementia, they are not always able to identify such capacity and may not always give people with dementia the opportunity to make decisions (discussed further below).

5. The implementation strategy devised by the Department of Health centred on the training of health and social care staff. Although written guidance was made available to carers, as there was no information campaign undertaken to raise awareness of this law, there remains a need for the Department of Health to initiate a media campaign to promote understanding of this law among people with dementia and their families and to raise public awareness of the human rights of people with dementia. As well as information, families and carers may need advice on assessing capacity, understanding communication (including non-verbal) and practical strategies for involving people with dementia in decision-making (including major decisions). We have produced an information film aimed at raising awareness among the public, carers and people with dementia about the importance of supporting decision-making in dementia. We have also produced a guide for people with dementia and their families which provides practical advice on managing and supporting decision-making (also available in urdu and polish). The resources are available from the project website: http://www.applied-social-
In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.

It is important to note that carers may also need to obtain advice on assessing capacity and supporting decision-making from health and social care professionals and voluntary organisations (such that written guidance may not be sufficient).

7. Our research found that carers and people with dementia appeared to lack explicit awareness of the Act (although it was not always possible to explore this complex issue with the latter). Nonetheless, some people with dementia were able to highlight the importance to them of having a say in their lives and being able to make their own decisions. In addition, some carers showed implicit understanding of the ethos of the Act in relation to the importance of involving people with dementia in decision-making and acting in their best interests where appropriate. Overall, our study found that carers generally involved their partners with dementia in everyday decision-making processes. However, carers sometimes made decisions on behalf of people with dementia when they still had the capacity to make these decisions themselves. There were notable gender differences in that wives who were carers tended to be more facilitative of decision-making by their partners with dementia when compared with male carers, at least in relation to minor decisions such as what to wear or eat (see Boyle, 2013c). Hence, ongoing implementation of the Act needs to take account of gender differences in acknowledging and facilitating capacity to ensure that the decision-making rights of women with dementia are upheld.

However, it was also found that carers of both sexes often did not involve their partners with dementia in major decision-making or the people with dementia were marginalised in such decision-making processes (such as decisions about using care services, moving house or Designating a lasting power of attorney), even when they had the necessary capacity. As this often appeared to be related to additional disabilities (particularly impaired speech) which made decision-making more challenging, this indicated that carers need advice on understanding and facilitating communication but may also lack awareness that communication difficulties do not equate with a lack of decision-making capacity. Hence, carers still need advice and support in this area. However, carers also need to be made aware of the importance of involving people with dementia in major decisions when they still have the necessary capacity (see Boyle, 2013c,d). Likewise, professionals who work with carers (for example, in undertaking assessments re care services) need to ensure that they involve people with dementia in such decisions. As carers often exert quite a lot of decision-making authority more generally, it is important that ongoing implementation of the Act ensures that people with dementia are nonetheless given opportunities to make decisions where they still retain capacity.

16. Whilst the DOLS do not apply in domestic settings, carers may need guidance on how to balance maintaining safety and minimising risk with promoting wellbeing and avoiding inappropriate constraints on liberty.

19. Our research found that carers who took over the management of finances sometimes took over the financial decision-making as well without fully considering whether their spouses still had the capacity to make specific financial decisions (even in order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.)
if they lacked the ability for practical financial management). In addition, some people with dementia were marginalised in decisions about designating a Lasting Power of Attorney (such as property and financial affairs), as carers tended to take the lead here or even take control (see Boyle, 2013d). However, as our research focused on everyday decision-making more generally, more specific research is needed which explores in-depth the particular processes leading up to a decision to make an application for a Lasting Power of Attorney. There is also a need for the Office of the Public Guardian to monitor the application process for LPAs when someone has dementia to ensure that their decision-making rights are supported in practice.

See also the following publications (copies can be provided if necessary):

2) Boyle, G. (2013d) She’s usually quicker than the calculator’: Financial management and decision-making in couples living with dementia (2013d), Health and Social Care in the Community.

7 August 2013
In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Bracknell Forest Council – Written evidence

Overview and context

1. To what extent has the Mental Capacity Act 2005 (MCA) achieved its aims? The Act has created a clear framework for people who support people aged 16 and over, who may lack capacity. The act has set a clear and consistent framework for the assessment of capacity.

2. Which areas of the Act, if any, require amendment; and how?

Schedule A1 (DoLS) of the act would benefit from amendment. Currently the act does not define what a Deprivation of Liberty is, and therefore it is left to Best Interest Assessors and (where required) the courts to interpret what may constitute a deprivation. This may lead to inequalities.

3. At the core of the MCA are its principles and definitions of capacity and best interests. Are these appropriate?

Yes.

Implementation

4. To what extent have the five principles of the MCA been implemented in frontline practice? What evidence is available to assess this? Is there a satisfactory balance between enablement and protection?

The implementation of the principals and the Act more generally is inconsistent across the country and between sectors. Providers of social care are generally well informed about the principles of the act, but this is not consistently replicated across other sectors (i.e. the NHS, Housing etc).

Evidence of compliance with the Act is down to organisational discretion. As a local authority we undertake regular quality audits of compliance with the act embed learning into staff and organisational development. Currently the Care Quality Commission does not routinely monitor providers’ compliance with the principles of the Act.

The balance between enablement and protection is a challenging area for front line practitioners, but the Act does provide a framework for staff to work within. It is our view that the Act and the code of practice strike the right balance in this area.

5. How effective was the Government’s implementation plan? What measures were taken to ensure that professionals and families of those who lack capacity know about and act in accordance with the provisions of the MCA? Has it led to sustainable change?

The implementation of the act was limited; there was no public awareness campaign of the act, which has resulted in a limited knowledge of the Act across the general public.
6. Is the Act widely known and understood by professionals required to implement it? How does this differ across different sectors, such as health, social care, banking and others?

As stated previously the understanding of the Act, its principles and practical application varies greatly between sectors. The NHS, Banking and Housing sectors require particular attention to ensure the Act is understood and implemented.

7. Is the Act widely known and understood by those who are directly affected by it and by their non-professional carers? To what extent does the Act provide protection and reassurance for informal carers? Has the right balance between protection of the carer and protection of the individual lacking capacity?

A considerable amount of work has been undertaken locally to develop understanding of the Act with people who may lack capacity and their family/informal carers. However this may not be consistent across sectors, therefore if the person is not supported by the local authority then they and or their family/carers may not be aware of their rights under the act.

8. Has the Act ushered in the expected, or any, change in the culture of care?

There have been developments in this area, but practice remains inconsistent and is not routinely monitored by the regulator (where appropriate) so it is difficult to say with certainty what the national picture is.

9. Is there any evidence that the provisions of the MCA affect some groups disproportionately? If so, what data exists to compare representation across different socio-economic groups, Black and Minority Ethnic groups, and gender?

We have no evidence in this area.

Decision making

10. Are those directly affected by the Act being enabled and supported to make decisions for themselves to a greater or lesser extent than they would have been in the past? Does the means by which the decision is made – ‘general authority’, Lasting Power of Attorney, deputyship, Court of Protection – affect the quality of decision making?

Locally the principles of the act and best interest decision making are embedded within practice. The code of practice is very clear regarding supporting the individual to engage in the decision making process. However this is reliant on practitioners being aware of the Act and the code of practice, which as stated previously is not always the case across sectors.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
11. What evidence is there that advance decisions to refuse treatment are being made and followed?

We have no evidence in this area.

12. Has the MCA fostered appropriate involvement of carers and families in decision-making?

Family/carers are routinely involved in the decision making process (where appropriate), the Act has increased practitioners’ practice in this area.

13. Has the role of the Independent Mental Capacity Advocate (IMCA) succeeded in providing a voice for clients and an additional safeguard against abuse and exploitation for those who have no-one to speak on their behalf?

The creation of the IMCA role has been positive. It has ensured that people who lack capacity have had their voice heard and that where appropriate decision makers have been challenged regarding their proposed decisions.

14. Has the level of referrals to IMCAs met expectations? What are the reasons for the regional variations in the number of referrals?

Referral rates to IMCA vary dramatically from area to area. Referral rates locally have increased year on year, possibly as practitioners become more aware of the Act. However referral rates from the NHS (nationally) remain at a low level.

15. Are IMCAs adequately resourced and skilled to assist in supported or substituted decision making for people lacking capacity?

Yes

Deprivation of Liberty Safeguards

16. Are the safeguards in the Deprivation of Liberty Safeguards (DoLS) adequate?

The safeguarding should be broadened to incorporate people living in a private residence as well as those living or residing in a care home or hospital. Currently where a person living in their own home is thought to be being deprived of their liberty the relevant authority is required to make an application to Court of Protection or the High Court (under its inherent jurisdiction), this does not provide a timely response and is unduly burdensome.

17. Are the processes for authorisation, review and challenge of DoLS sufficiently clear, accessible and timely?

No - the application process is unduly burdensome and is difficult for front line staff to apply. The number of standard forms should be reduced and redesigned in a more accessible format, so that the individuals and their representative can be better informed of the assessment and outcomes.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Bracknell Forest Council – Written evidence

There should be an appeals process at a local level rather than having to refer issues of conflict/appeal to the Court at the first attempt, and supervisory bodies (local authorities) should have the ability to extend the period of authorisation following a review rather than having to undertake a new assessment.

It should also be noted that the application process itself could act as a deterrent for managing authorities, which may leave individuals without the appropriate legal safeguards.

The Court of Protection and the Office of the Public Guardian

18. Are the Court of Protection and the Office of the Public Guardian sufficiently understood and accessible to all? Are they operating effectively and successfully?

The role of the OPG and CoP is not widely understood. Further work is required to raise awareness of both the OPG and the CoP.

There are considerable delays in the OPG possessing an LPA application and the application forms are unduly lengthy for members of the public.

19. What has been the impact of the introduction of lasting Powers of Attorney (LPA), especially with regard to decision making on matters of personal care and welfare?

There has been limited uptake of Personal Care and Welfare LPAs. However where they have been granted they have allowed people to be proactive in identifying who they wish to make decisions for them should they lose capacity. Awareness of the role of an LPA for personal care and welfare should be increased.

20. What concerns, if any, are there regarding the costs associated with registering an LPA, or with making an application to the Court of Protection?

The application fee (£400) may not in itself act as a barrier, particularly as there are grounds for the fee to be waived. However as the application forms are both lengthy and complex people often require the assistance of a solicitor to complete the forms, which then increases the cost. If the application forms were to be simplified this may reduce the need for people to get legal support and therefore reduce the costs and increase the number of applications.

21. Is legal aid available and sufficient? What impact will the recent and proposed reforms to legal aid have?

We have no evidence in this area.

Regulation

22. Is the role of the Care Quality Commission in inspecting on the MCA standards adequate and appropriate? Is there a case for additional powers?

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
The Commission does not consistently monitor compliance of the Act in all inspections. Given that the Act is a fundamental part of the health and social care framework, we believe that the commission should monitor compliance in all inspections.

Failure to comply with the Act should be made a breach of the regulations.

23. Should other regulatory bodies, such as health and social care professional regulators, be acting in this area?

Again we believe that a failure to comply with the Act should be seen as a serious breach of professional standards and a proportionate level of sanctions should be attached to such a breach.

Other legislation

24. How well is the relationship with the mental health system and legislation understood in practice?

There is confusion within local inpatient services as to the role of the MCA. It would be beneficial if greater clarity was provided regarding the respective role and function of the MHA’83 (As amended) and the MCA.

Devolved administrations and international context

25. Does the implementation of the Mental Capacity Act differ significantly in Wales?

We have no evidence in this area

26. What lessons, if any, can be learnt from the approaches taken to mental capacity legislation in Scotland and Northern Ireland, or in other jurisdictions?

We have no evidence in this area

27. Is the MCA compliant with the United Nations Convention on the Rights of Persons with Disability (CRPD)? Are there lessons that can be learnt from the CRPD for the successful implementation of the MCA?

We have no evidence in this area

2 September 2013
Brighton and Hove City Council – Written evidence

This response has been developed following consultation with and feedback from practitioners across adult social care services in Brighton and Hove.

Overview and context: To what extent has the Mental Capacity Act 2005 (MCA) achieved its aims?

1. Overall the Act is well received as providing a clear statutory framework for practitioners to work within and for promoting a person centred, empowering, consultative approach, as well as accountability for decision making with vulnerable people. When applied, this has had positive outcomes for people both in terms of how/when decisions are made on their behalf and balancing protection against the benefits of living with risk. However there is also evidence that practitioners may lean towards maximising physical safety at the cost of other potential benefits.

2. The definition of capacity as ‘time and decision specific’ is challenging in that many decisions are not made in isolation at a specific time. The same decision for a person to manage their finances may be ‘simple’ in one context, and ‘complex’ in another e.g. when faced with attempts to exploit. Time and decision specific mental capacity assessments are more easily understood in relation to one off day to day decisions e.g. what to wear/eat today or one off more significant decisions e.g. where to live. Many decisions will have a bearing on other aspects of a person’s life either now or in the future, and expecting a person with significant impairments and complex care needs to evidence understanding of all the reasonably foreseeable consequences may be a tall order.

3. The Act has raised awareness of situational incapacity e.g. DL & Others V a Local Authority (2012)

Implementation

4. Awareness of the Act has increased locally within assessment services. Following training there is evidence of understanding of the status of, and showing ‘due regard’ to the Code of Practice, knowledge of the statutory principles and best interests’ checklist and navigation of the code for information on other provisions. However there are still issues with application of the principles in practice. Global statements about capacity remain, concerns about meeting the diagnostic criteria if the diagnosis is not clear/confirmed, misunderstanding the ‘presumption of capacity’ as a reason not to intervene (at all). Difficulties distinguishing unwise from incapacitated decisions can be a real challenge for even the most aware and experienced in applying the Act.

5. Practitioners may also invest more time in environmental and other manipulation to support ‘understanding’ of the information, but are less consistently ensuring that the information to be understood is relevant and adequate.

6. Anecdotal evidence suggests less awareness in provider and hospital settings.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
7. The CQC’s findings from the AMCAT self audit of MCA tool pointed to a low level of awareness and implementation in frontline services and poor practice in assessment. Some services have welcomed and partially understood and implemented aspects in a wrongheaded manner e.g. blanket assessments of capacity on admission to a residential placement. We have been aware of the danger of placement admission ‘forms’ referring to ‘mental capacity’ being used as a one off ‘tick box’ exercise, rather than the principles being applied on the ground on a day to day basis and within care planning.

8. The Code of Practice is an accessible and readable resource, but paints a rather rosy picture of outcomes when the Act is applied. The code could provide more guidance about competing interests e.g. needs of carer family/family others when considering best interests and least restrictive alternatives. The Equalities Team have requested specific reference to all equalities groups when applying the act rather than current general reference to e.g. culture, wishes.

Decision making

9. Local indications are that the MCA has fostered greater inclusion and collaboration/consultation both within and between practitioners and informal carers/relatives, but that carer’s/relatives knowledge of the Act is limited and in particular their role and authority as decision makers on a day to day basis.

10. Current guidance assumes a level of skills/knowledge amongst professionals applying the Act which they may not have, particularly where needs are complex, capacity may be fluctuating or borderline. Securing specialist opinion may not be easy and can be costly both in time and money. Notwithstanding the ‘balance of probability’ there is the danger of people being incorrectly assessed as having or lacking capacity.

11. The act quite rightly aims high, but more guidance is needed around ‘proportionality’ as to be faithful to principles of the Act may require significant investment in terms of time amongst other competing demands and reduced resources.

12. The Act’s emphasis appears to be on capacity to ‘make a decision’ in theory, with insufficient reference to the person’s ability to then ‘execute’ that decision. In ideal settings and with support, a person may meet the requirements of the 4 stage test, but may not, in the real world and/or due to e.g. impulsivity be able to carry out that decision. Mood, emotion and motivation add to the complexities of how people make decisions (regardless of any ‘impairment’ and it can be very difficult to establish when decisions are being influenced by the ‘normal’ human condition and related inconsistencies, or by an impairment in the decision making process. This is often raised as an issue where risks are secondary to e.g. addictions or relationships.

13. The IMCA provisions within the Act have provided a valuable voice and source of support to the person, as well as a helpful independent resource for decision makers. Locally decision makers have welcomed the IMCA role in both reinforcing the appropriateness of decisions or in providing alternative suggestions and challenge to support the achievement of a least restrictive alternative. Within in order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
hospital settings, in addition to issues of awareness, different views about what constitutes ‘serious medical treatment’ may result in IMCA not being instructed as the legislation intends.

14. An increase in remit of the IMCA service or availability of general and specialist advocacy services for vulnerable people would increase protection for those who currently do not meet the criteria. Whilst the support of relatives in supporting best interest decision making is not to be undervalued, there are situations where it would be incorrect and potentially divisive to judge the relative ‘inappropriate to consult’ although the relative may be unable to really represent the person e.g. due to their own values/ issues or may not feel able to challenge ‘authority figures’ or decisions they do not agree with.

Deprivation of Liberty safeguards

15. Whilst The Deprivation of Liberty Safeguards (DoLS) are welcomed as filling the ‘gap’ in the law, to prevent the arbitrary and unlawful detention of people who lack capacity, it is not clear that this gap has been filled. It is over reliant on managing authorities to understand the safeguards and establish whether the thresholds for deprivation are or are likely to be reached. The Safeguards provide scrutiny and protection to those that are brought within its remit, but many may not be coming to the attention of the SB including self funders, and those that do, may be a consequence of existing advocacy. Further/clearer guidance is needed for managing authorities, and effective inspection or other arrangements to support compliance.

16. The Safeguards are experienced as bureaucratic and confusing. The terminology ‘deprivation’ can incorrectly suggest a negative experience for the person and a negative reflection on care providers. There needs to be a much clearer definition of ‘deprivation of liberty’ more akin to common understanding. Case law which introduces notions of ‘relative normality’ and ‘motive’ provoke hugely interesting debate but may not be helpful on the ground where a scenario which objectively presents as a deprivation, is considered not to be so.

17. The significant majority of requests for standard authorisations are following the issuing of urgent authorisations and may be a reactive response, and not eg following a process of reviewing care plans to reduce restrictions. This imposes significant time constraints (7 day turn around for assessments) on the supervisory body to ensure completion of the assessment process. There needs to be more guidance and emphasis on care planning leading up to and during placement where the actual and likely types/degrees of restriction are carefully considered and mitigated as far as possible and clearer expectations on managing authorities (MA) to take steps to reduce restrictions in advance of issuing an authorisation. This may reduce incidences of managing authorities ‘waiting’ for the BIA to make decisions and recommendations or conditions that that would have been appropriate for the MA to initiate themselves.

18. A lack of an automatic or straightforward appeals process leaves the person insufficiently protected and recourse to the Court of Protection as the only source of independent appeal may in some cases reduce inclination for objections to be
raised on behalf of the person but conversely may increase referrals to the Court which might be better dealt with through an alternative process in the first instance.

19. Whilst the Safeguards were introduced to fill a gap in the law, there needs to be greater account of the general ‘well being’ of vulnerable people who may not, in the eyes of the law as it stands be ‘deprived’ but for whom the quality of life may be poorer than that of a ‘deprived’ person by virtue of eg limited opportunities and restrictions within their living environment.

20. There remains some confusion about the relationship between DoLS and Safeguarding and further guidance is needed e.g. around appropriateness of use of DoLS to manage ‘contacts’ pending resolution of disagreement about best interests or application to the Court of protection.

Court of protection

21. There needs to be clearer guidance and opportunities for conflict resolution in DoLS and the wider MCA – at what point should a decision go the COP? Should there be more formal ‘checks/balances’ outside of the best interest process, but which sit outside the specific jurisdiction of CoP such as a local tribunal, where disagreement about some best Interest decisions can be considered independently of the designated decision maker, with potential for agreement through this process before a referral to the court of protection is considered necessary.

22. Could some decisions requiring a legal mandate and which might be significant e.g. termination of tenancy, but evidenced as un-contentious following the best Interest process be managed differently/within shorter timescales than is currently the case. This would reduce costs to the person or state (housing costs/benefits for a property that is not being lived in) and would more quickly free up unoccupied housing association and council properties for re-let.

Other legislation

23. The overlap between DoLS and MHA needs further clarification to avoid the ‘new Bournwood gap’ where a person who fails the ‘eligibility test’ is then assessed not to meet the criteria for detention under the MHA. There may be an under use of S3 MHA with numbers of older incapacitated ‘informal’ patients on psychiatric wards, discharged from S2 MHA, but none the less ‘not allowed to leave’.

24. The Act appears to be at odds with the UN Convention on the Rights of Persons with Disabilities, Article 12(2) provides that people with disabilities may enjoy legal capacity ‘on an equal basis with others in all aspects of life’. Consideration needs to be given to how the MCA in its current form does not lead to the ‘sanctioning’ of discriminatory or oppressive practice.

29 August 2013

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Bristol Mind IMCA Service – Written evidence

Bristol Mind has provided the IMCA Service for UA Bristol since 2007. We appreciate the opportunity to contribute to this important enquiry, but would like to limit our contribution to observations from our perspective as IMCA providers. Please note, the numbering of our paragraphs does not correspond to the numbering in the Call for Evidence document.

1. Overall, the legislation and Code of Practice provide a useful framework for decision making for people who lack capacity (or who may do so in the future). The guidelines for the involvement of the IMCA and for the decision making process are very clear. However, implementation is still patchy, due to a lack of or inaccurate knowledge on the part of decision makers. We suspect this is part of the reason for different referral rates across the country and between responsible bodies within the same region. It is in the nature of things that staff come and go, and in our view the training programmes provided by Responsible Bodies need to be extended and on-going until understanding of the MCA is properly embedded.

2. The role of the IMCA is still not understood as having legal status or taken seriously by some decision makers. It may help to address this if the role of the IMCA were extended to include a more formal role in monitoring the implementation of the Act (eg better tie-in with regulatory bodies such as CQC). There should also be some clearly identified additional funding to enable IMCA’s to have an annual programme of continuing professional development. This would help to reflect the complexity of the role, and the significant skills and experience required.

3. It has been suggested that the IMCA role could be extended to include litigation friend work. We would be in favour of this as we often know the person better than the OS, however any extensions to the IMCA role would need to be adequately resourced as we are already at full capacity fulfilling our existing statutory duties under the MCA 2005.

4. In some respects the level of referrals to IMCA Services across the country has been lower than first forecast, however the time taken per case is proving to be far higher than initially anticipated, even for relatively straight-forward cases. In Bristol we are increasingly being instructed for very complex cases, with multiple eligible decision components (including complex adult protection issues).

5. Bristol City Council estimates it’s Black and Minority Ethnic communities make up around 16.5% of the total population, however even where differential birth rates and recent immigration factors are taken into account, the rate of referral for BME groups appears to be very low. Some work needs to be done to understand and address the reasons for this. With regard representation across different socio-economic groups, IMCA’s have no access to any socio-economic information in respect of the people referred to them, as such it is hard to make objective comment about this. That said, it is our perception that very few accommodation
referrals involve people who are self-funding or who will go into the more expensive forms of care.

6. With regard to IMCA’s providing a voice and an additional safeguard for those who have no-one to speak on their behalf, it is likely we are still not receiving all the statutory referrals we should, it is also unlikely to be the case that the LA is exercising their discretionary powers to instruct as often as they might. While we do believe we provide adequate safeguards for the people referred to us, we can only provide these safeguards and a voice when referrals are made.

7. On a more general note, in our experience there is still a tendency to understand the Act as a framework for making decisions for or on behalf of a person rather than encouraging and maximising their participation in the decision making. This tension between beneficence on the one hand and the autonomy of the person on the other still leaves too much room for misinterpretation and parochialism, and in our experience there is still a tendency among professionals to want to make the “safe” choice (to be risk averse).

8. Presumption of capacity is not always in evidence, and when it is can often be misunderstood. We encounter assumptions being made about a person’s capacity eg on the basis of a person’s condition, and practitioners sometimes conflate capacity and best interests (because a person wants an outcome that others think is not in their best interests, they are assumed to lack capacity). Capacity is sometimes assessed in a blanket way rather than in a decision-specific way and by means of inappropriate or inadequate methods (such as MMSE).

9. Assumptions can still be made about what constitutes best interests and there appears to be little understanding of or reference to the MCA best interests framework in some contexts, particularly medical.

10. Although the MCA is now in its 6th year, there seems to be little or no recording or monitoring of incidents of non-compliance with the Act, unless there is a related “incident” such as a death. It is also unclear how responsible bodies maintain and monitor the level of knowledge about the Act in respect of practitioners / decision makers. At Bristol Mind we frequently become aware of incidents of non-compliance with the Act (eg where medical procedures or moves of accommodation have been carried out without instructing an IMCA and where there was a statutory duty to do so). There is currently no reporting mechanism for these events, and seemingly no negative outcomes for the responsible bodies involved. In our view there needs to be a more robust process for regulating breach of duty, or else compliance with the MCA will only ever be seen as a “tick-box” exercise.

11. We support the call for some kind of MHA tribunal system for bread and butter welfare cases to make appeals less costly and cumbersome and more readily accessible for the person and their representative. Similarly, we have experienced that making and registering LPA’s is prohibitive for many individuals in terms of complexity, cost and the time it takes to process applications.
We hope our contribution is helpful. We would be happy to provide further information to clarify or illustrate any of the above points if requested.

This evidence is provided on a corporate basis by the Bristol Mind IMCA Service. As we are submitting this document electronically we are unable to hand-sign: please advise if you require a hard copy.

30 August 2013
British Association of Brain Injury Case Managers – Written evidence

I write to provide a summary of representational evidence collated from members of the British Association of Brain Injury Case Managers (BABICM) to inform the House of Lords Select Committee on the Mental Capacity Act 2005.

I am Jackie Dean, Member of the Council of the Association and Retiring Chairperson. I was nominated to canvass our membership regarding their experiences of the Mental Capacity Act in practice and its impact on the vulnerable people that they support. I understand that several of our membership have written to the Select Committee independently and in response to the consultation, but we also invited those, who perhaps did not feel able, to present their experiences. There is a summation of these responses attached as an appendix to this letter.

BABICM has existed since 1996 as one of the two main case management organisations in the United Kingdom representing the views of approximately 400 members, the majority of whom are practising case managers. These are generally health and social care professionals with substantial experience who work with people with catastrophic injuries, including severe acquired brain injuries.

Case management has been defined as an active process devoted to the co-ordination, rehabilitation, care and support of people with complex, clinical needs and their families. It aims to facilitate their independence and improve their quality of life whilst acknowledging safety issues. (BABICM)

Brain Injury Case Managers therefore are in the position of exploring, managing and assisting in the assessment of Mental Capacity on a regular basis, and have considerable stakeholding in the outcome of the findings of this review.

Summary of findings

Review of the information forwarded by the membership carried several common themes and concerns. These may be summarised as:

• Lack of understanding of brain injury by assessors and decision makers, in particular by local authority social workers
• Poor practice in assessment and without consideration of the experiences of those that know the person well; i.e treating therapists, support staff, family and carers- either not exploring these or disregarding them
• Face value acceptance of clients with executive difficulties and high level of intellectual abilities that present well in a structured assessment situation but are unable to carry out their decisions in "real life" situations
• Social workers assessing clients on a "here and now" decision without considering wider perspectives and evidence that impacts on complex decisions.
• Decision making by assessors failing to understand the interaction of decisions.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
British Association of Brain Injury Case Managers – Written evidence

- Failure to understand the impact of insight or fluctuating insight on decision making and to place decisions in context of the individual and factors that impact on that decision
- Failure to understand the impact of emotion and mood on decision making
- Failure to understand the impact of the assessor's own biases and factors influencing their decision regarding capacity; including organisational pressures, pressures of the litigation process, financial constraints, cultural values, paternalism and management of risks
- Common use of the implication that a person has capacity as a means to remove accountability and responsibility and as a reason for non-provision of services.
- Use of advocates and IMCAs that have no understanding of the nuances and complexities of brain injury
- Reluctance from Financial Deputies and others to challenge decisions as a consequence of cost, and variability in outcomes meaning that challenges are unpredictable.
- Concerns regarding risks and vulnerability of brain injured people and their families as a consequence of decision making by ill informed assessors of Capacity

**Particular difficulties in acquired brain injury**

Severe brain injury presents complex challenges when assessing capacity. This is particularly difficult within the linear framework of the Act where people present with executive ability dysfunction. Particularly associated with injuries to the frontal parts of the brain and integrated brain systems, executive functions may be defined as:

"*those higher-order cognitive abilities that encompass the generation, selection, planning and regulation of responses that are goal directed and adaptive, given the contextual demands placed upon the individual.*"

(Lezak 1983)

Executive disorders are characterised by combinations of impairments in initiation, planning, sequencing, inhibition, flexibility of thinking and monitoring of behaviour and thinking. These abilities are critical in

"*enabling a person to determine goals, formulate new and useful ways of achieving them, and then follow and adapt this proposed course in the face of competing demands and changing circumstances; often over long periods of time. They enable people to resolve effectively the challenges they encounter in everyday life and cope with new situations*"

(Burgess and Simons, 2005)

It is considered that it is within the assessment of weighing of information and using information that these issues are particularly relevant. Evaluation of executive difficulties are notoriously difficult to identify within a formalised assessment process, where the very structure of the setting and assessment process sets a context within

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which these very skills are maximised. A person with executive difficulties may well identify that they understand the process, make an apparently logical decision when interviewed, be able to place their decision within a goal, be able to identify the possibility of risks to themselves but behave in a contrary fashion when placed in a context of everyday life. Too often decisions are made based upon response in interview with limited or no consideration of the history of the person’s actions and behaviours in context of everyday living and over time.

"Deficits of executive function that appear quite mild in the examination room can nevertheless have a devastating effect on everyday functioning"

(Burgess et al., 2009)

It is critical, therefore, that the assessor of Capacity has training in and understanding of brain injury and in particular the role of executive dysfunction in particular if insight is lacking.

Some individuals have problems sequencing thoughts or exercising judgements regarding risks, or generating alternative options. Too often the assessor will not make attempt to consider the individuals understanding of the risks associated with their actions or the benefits of options. (Reid-Proctor, Galen and Cummings. 2001)

Again, it is difficult to evaluate the effects of the impact of impulsivity, of reduced mental flexibility, or poor social monitoring on decision-making within a structured assessment process. Too often assessors define poor decision making as active choice, or inflexibility of thinking and rigidity as consistency and clear opinion. Individuals with executive difficulties may have problems forming a concept about the future and the impact of their decisions upon this, may have difficulties in weighing up consequences, may form false beliefs about others, may have an altered understanding of social norms, have difficulty problem solving or shifting their beliefs when outcomes are not as they have planned or considered. (Ajzen and Fishbein 1980) (Powell 2004) (Herbert 2009)

Whyte et al (2003) compared results of "capacity assessments" carried out by a medical practitioner and a neuropsychologist and identified that those patients with executive functioning problems who presented well at interview were most likely to be judged as capable by the assessing doctor but as lacking capacity by the neuropsychologist. It is important, therefore, that the assessment interpretation is carried out by someone with the necessary brain injury skills and experience to understand the wider perspective. This is repeated on a regular basis by social workers trained in the assessment process but not in the nuances of acquired brain injury.

Other factors should be taken into consideration in a wider context that impact on decision making. Mood and emotional drivers can influence all of our decision making, as can social and cultural norms. All of us make decisions based upon these factors, and so desires and influences, as well as previous lifestyle choices, should be taken into account when considering a person’s wishes. This should not, however, remove exploration of the level of influence the external environment and internal emotional environment are influencing a person’s decision making.

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British Association of Brain Injury Case Managers – Written evidence

Poor decision-making may be due to either impaired cognition and emotional regulation, or impulsive decision making that is overly responsive to emotional cues. History of an individual's behavioural patterns would indicate whether there is a failure to learn from negative experiences.

"Decision making can be undermined by too little or too much emotion, with such patients seeming to suffer a deficiency of 'emotional intelligence' despite preserved IQ"

(Bar-On et al/2005)

Brown and Marchant (2011) have commented upon the "well-established body of research that points to the contribution of, and sometimes the primacy of, emotions and mood in determining the outcome of decision making. They go on to note that "Emotions seem to provide an essential driving force in deciding and acting that has been edited out of the MCA but not out of these real-life situations.

Emotional decision-making is more likely where a person is under cognitive pressure as a consequence of an acquired brain injury. This is an important factor that should be absorbed within the assessment process.

I attach responses to the specific questions raised within the consultation but would respectfully ask that this letter and appendices are also submitted for consideration. I hope that this is helpful, and please do not hesitate to contact BABICM should you require further clarification.

Yours faithfully,

Jackie C Dean, Dip COT
Occupational Therapist and Brain Injury Case Manager
Retiring Chairperson, British Association of Brain Injury Case Manager

References:


New York


In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
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Overview and content

1. To what extent has the Mental Capacity Act 2005 (MCA) achieved its aims?

2. Which areas of the Act, if any, require amendment and how?

3. At the core of the MCA are its principles and definitions of capacity and best interests. Are these appropriate?

As outlined within the attached letter, there are difficulties associated with the complexity of decision making and the combination and context of decision making. Looking at one decision in isolation is not always helpful and leads to further difficulties. For example, a client is asked about a decision as to where they might live, and then about a decision as to the level of care that they might receive. He is found to have capacity for the first decision but not the second. These two factors may be inextricably linked and then the decision making is about the consequences of both decisions and their interaction. Too often it is the wrong question being asked by the wrong person with limited understanding of the person or their specific difficulties.

Members of BABICM consistently identify that social workers being asked to conduct these assessments are not looking at the wider picture, do not have the skills to place decision making within context and are regularly not following the best practice guidelines to liaise with relevant others and families in order to complete the assessment.

The principles do not transparently consider the difficulties that brain injured individuals have between assessment and real life, the influence of emotional decision making and multiple decision making, fluctuating capacity and insight. At least, these factors are regularly not being taken into account in practice.

It is noted that some of the presented evidence would indicate simplification of the forms, but there is concern that current assessment processes are already over simplified. Social workers appear to be trained in completion of capacity assessment but not within the need to identify the particular level of knowledge required to complete the assessment, or the wider context of the disability of the person that they are assessing.

Implementation

4. To what extent have the five principles of the MCA been implemented in frontline practice? What evidence is available to assess this? Is there a satisfactory balance between enablement and protection?

5. How effective was the Government’s implementation plan? What measures were taken to ensure that professionals and families of those who lack capacity know about and act in accordance with the provisions of the MCA? Has it led to sustainable change?

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
6. Is the Act widely known and understood by professionals required to implement it? How does this differ across different sectors, such as health, social care, banking and others?

7. Is the Act widely known and understood by those who are directly affected by it and by their non-professional carers? To what extent does the Act provide protection and reassurance for informal carers? Has the right balance been struck between protection of the carer and protection of the individual lacking capacity?

8. Has the Act ushered in the expected, or any change, in the culture of care?

9. Is there any evidence that the provisions of the MCA affect some groups disproportionately? If so, what data exists to compare representation across different socio-economic groups, Black and Minority Ethnic groups, and gender?

The evidence from our membership would indicate that the principles are not being adequately followed within frontline practice, again as a consequence of people being assessed by people with inadequate knowledge of executive difficulties, the complex cognitive processes involved in an assessment of capacity in a brain injured individual, the role of insight and environmental cueing and emotion within decision making.

Reports from members would indicate that statutory services are asking about capacity as soon as there is a difficult decision to make, assessments are inadequate and then if a person is deemed to have capacity then this is used as a rationale to not provide services as a matter of client choice. It is argued that the two issues are not synonymous. Capacity and assessment of need are not always the same thing. Assessment of capacity is used as an economic tool to justify lack of provision, leaving the disabled person unprotected and those trying to protect them with no means to provide services.

It is the experience of our members that there is mixed understanding amongst professionals regarding the issue of capacity. Many frontline professionals indicate that they are not trained to assess issues around capacity at even a simple level, whilst others formulate a global view of capacity; for example indicating that as a person lacks financial capacity and have an appointed Financial Deputy they also do not have capacity for other areas of their life.

**Decision making**

10. Are those directly affected by the Act being enabled and supported to make decisions for themselves to a greater or lesser extent that they would have been in the past? Does the means by which the decision is made - 'general authority', Lasting Power of Attorney, deputyship, Court of Protection - affect the quality of decision making?

11. What evidence is there that advance decisions to refuse treatment are being made and followed?

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
12. Has the MCA fostered appropriate involvement of carers and families in decision making?

13. Has the role of the IMCA succeeded in providing a voice for clients and an additional safeguard against abuse and exploitation for those who have no-one to speak on their behalf?

14. Has the level of referrals to IMCAs met expectations? What are the reasons for the regional variations in the number of referrals?

15. Are IMCAs adequately resourced and skilled to assist in supported or substituted decision making for people lacking capacity?

Again, it is the experience of our members that decision making is being based on inadequate assessment of brain injured people, and consequently the decision making process becomes flawed.

IMCAs are infrequently engaged when their input would be helpful. It can be identified that the person has family or a case manager to represent their view, but then the view of those people is disregarded in practice. Where IMCAs are involved they again seem to lack understanding of brain injury and the context of insight, executive functioning and emotional decision making on individuals. Consequently they can be counterproductive to the rehabilitation process that is aiming to assist the individual.

In the experience of our members there is poor balance in the seeking of family members' viewpoints in relation to best interest decision making and assessment of capacity. The family opinion is either disregarded or taken as paramount without regard for clinical or historical context. Often, as a result of environmental bias, individuals are overly influenced by family members and will agree with their opinion which is then accepted by the assessor as the opinion of the individual.

Deprivation of Liberty Safeguards

16. Are the safeguards in the DoLS adequate?

17. Are the processes for authorisation, review and challenge of DoLS sufficiently clear, accessible and timely?

No members made comment with regards to this. The experience of the author would indicate that the process is complex, lengthy, and confusing to staff working with injured people. There is confusion between assessors as to what constitutes a deprivation of liberty, and again, in understanding whether a person is volitionally participating in a process. The outcome is that vulnerable people are not protected. In the authors practice, safeguarding issues of abuse continue to be raised far more frequently than DoLS.

The Court of Protection and the Office of the Public Guardian

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
18. Are the Court of Protection and the Office of the Public Guardian sufficiently understood and accessible to all? Are they operating effectively and successfully?

19. What has been the impact of the introduction of Lasting Powers of Attorney (LPA), especially with regard to decision making on matters of personal care and welfare?

20. What concerns, if any, are there regarding the costs associated with registering an LPA, or with making an application to the Court of Protection?

21. Is legal aid available and sufficient? What impact will the recent and proposed reforms to legal aid have?

Experience indicates that the general public have limited or negligible understanding of the existence and workings of the Court of Protection. The processes, despite being reviewed, remain bureaucratic and costly and the latter impacts on decisions being taken to the Court. The image of the Court has not been assisted by media focus. Additional concerns are raised in this regard with the legal aid reforms. Already members are providing colloquial account that issues are not being pursued to Court as a consequence of the costs and uncertainty of outcome. This cannot provide people with access to protection and safeguarding. A role of the Court of Protection is to challenge decision making, but this cannot happen if people avoid taking decisions to the door as a consequence of affordability.

Regulation

22. Is the role of the Care Quality Commission in inspecting on the MCA standards adequate and appropriate? Is there a case for additional powers?

23. Should other regulatory bodies, such as the health and social care professional regulators be acting in this area?

The role of the Care Quality Commission at an implementation level remains again dependent upon understanding of brain injury when inspecting. The Care Quality Commission process has notably failed to identify concerns and it remains to be seen whether the current changes will improve this situation. The increasing varieties of environments and expanding models of care continue to provide challenges to this system and there are services and clients that continue to fall through the net.

Various Professional Bodies have gone some way to educating their membership about their responsibilities under the MCA and some have produced guidelines to assist. It is considered that more regulation will compound the current problems, and become increasingly unwieldy. Training cannot go amiss, but in relation to the need to understand and have experience and skill in the needs of the client group being assessed in addition to completion of the mechanics of the process.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Other legislation

24. How well is the relationship with the mental health system and legislation understood in practice?

Practitioners continue to struggle with both. It is experience that mental health practitioners do not have a good understanding of the MCA and also of acquired brain injury. It is experience of members that people with acquired brain injury are often difficult to get assessed under the MHA on account of the very issue that they have an acquired brain injury, yet social workers assessing the same clients consider that they have capacity for the reasons indicated above. The vulnerability of this client group is exemplified by the numbers of people with acquired brain injury within prison, in drug services and that are homeless.

Devolved administration and international context

25. Does the implementation of the Mental Capacity Act differ significantly in Wales?

26. What lessons, if any, can be learnt from the approaches taken to mental capacity legislation in Scotland and Northern Ireland, or in any other jurisdictions?

27. Is the MCA compliant with the United Nations Convention on the Rights of Persons with Disability (CRPD)? Are there lessons that can be learnt from the CRPD for the successful implementation of the MCA?

The number of cases that are being overturned on Appeal on the basis of Human Rights would tend to indicate that there are failings within the current process. There are apparently anomalous judgements that would tend to indicate that the linear process of isolated decision making fails to consider the interaction and impact of the real world.

Appendix 1

Anecdotal Evidence presented to BABICM

Very briefly then, my concerns lie with the fact that the Act does not really consider vulnerability, pressure and undue influence (Denzel Lush, BABICM newsletter 50 Autumn 2011) thereby seeming to provide inadequate safeguards for clients who have cognitive impairments as a result of acquired brain injuries that leave them easy prey to predators.

I agree entirely with the suggestion made in Jackie’s earlier email that issues with lack of insight, loss of executive functioning and the role of emotion in decision making are highly relevant issues which can be all too easily misunderstood by those without the necessary experience in working with individuals who have acquired brain injury.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
For example, in my experience, many individuals with brain injury find it well-nigh impossible to say 'no' to requests for money and even though they know they should be refusing and want to refuse they don't because they don't want to make life difficult for themselves. They don't think at the time about consequences and are unable to deal with the situation in any but a reactive way - which all too often creates greater difficulties later on.

Angela Washington, Independent Case Manager, Midlands

I'm relatively new to working with people who have brain injuries so my observations are on a small group of people. I have been quite surprised that when people are judged to not have capacity to manage money this seems to be being done as a blanket statement and is not being applied to individual situations. When I have done MCA training I have always been taught that it needs to apply in the appropriate moment and the person needs to be given support to help them understand the decision which needs to be taken, not as a blanket statement. At the moment I am working with a man who is deemed to not have capacity to manage money, yet he can budget and organise how much he's going to need for the day for food etc. He can go into a shop, knowing what he wants to buy, with the appropriate money and can count his change out and think about what he wants to do with the rest of the money. This demonstrates to me that he has the ability to manage his day to day money. It has been a difficult decision to challenge as it seems to suit the legal case which is going through that he doesn't have capacity.

New case manager - social worker

I am extremely concerned about persons without specific brain injury experience carrying out capacity assessments. I had an experience where Social Services requested a capacity assessment but would not recognise the assessment provided by the treating private neuropsychologist. None of the social services persons involved had brain injury knowledge or experience. They clearly did not appreciate the complex and fluctuating behaviour resulting from this client's dysexecutive difficulties/ frontal lobe damage.

Fortunately I as brain injury case manager was able to steer Social Services towards having an assessment by another neuropsychologist (which the client then had to pay for), rather than by the Social Services 'medic' who did not have brain injury experience.

People with acquired brain injury continue to fall outside any of other types of better established services

(e.g., mental health, learning disability) and therefore all too often, their needs remain mis-understood and unmet. Case manager, South of England

I am currently working with a client and it has been difficult to ascertain the capacity issue with regards to her ability to run her own finances. It was not until she started to run out of the interim payments, and her spending continued in the same routine way, that there was clear evidence, to my mind, that she was not capable of controlling her money.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Many of her symptoms, such as impulsivity, could make her decisions be easily construed as making an unwise decision, and it was not until she did not have the money to spend that it was clear that it was not something that she was choosing to do, rather something that she had to do as a result of the injury she suffered.

The solicitors and GP are not easily convinced of the complexity of brain injury presentation but unfortunately they very much act as 'gate-keepers' to the right help being accessed.

I sometimes wonder if the fact that a person is able to perform in some areas makes people shy away from taking action in others, especially if it is likely to be met with adversity from the individual.

Case Manager, OT- South of England

Despite my repeated requests to the Health Authority and Social Services Dept that my client's wishes as well and capacity be sought and assessed, neither the Health or Social Services teams responsible would take on this issue. Each department pushed it back to the other.

Both Health and Social Services teams backed away and declined to act until the issue was forced by the CoP.

A very time specific health and social crisis, that had to be taken to the Court of Protection by initially the Deputy then taken on by the Official Solicitor, before a capacity assessment was agreed to by the mother of the adult client and the Health Authority- via a psychiatrist experienced in acquired brain injury.

Case manager- South of England

1. Man with TBI [60 yoa] avaricious ex-wife appointed by his two sons as his Deputy. Man was deemed not to have capacity due to a very severe psychiatric presentation of an enduring delusion that he was from another planet. - He had lost 5 years of memory and this was his way to make sense of the fact that everything looked slightly different. Ex-wife manipulated and took advantage of his funds at every opportunity. In fact the client was perfectly able to make sound and sensible decisions when he wasn't being bullied by his family. Following a safeguarding meeting, I organised a letter to the CoP countersigned by 6 other health and social care professionals providing 18 pages of evidence illustrating both abusive practice and his ability to make decisions given the right emotional environment. However the CoP did not reverse the ex wife's role as Deputy and the client remained in fear of her.

2. Man with TBI at 19. Patient under Court of Protection -Court case has already been heard about the issue of his capacity & court found he did not have capacity. Needs a 24 hour care package as extremely vulnerable with usual kaleidoscope of TBI presentation. Has been well supported by local social service department with a high direct payment combined with some private funds. Has now moved out of area and is undergoing a new care assessment with a new team. He has appalling...
insight and because his support team has enabled him to create an excellent quality of life, he believes that he is far more capable than he is. If he was aware of the extent of his disability this would generate a devastating depression which would be awful for him and very difficult for staff to manage.

In spite of the fact he remains a patient he "masks" very well. May need a new capacity assessment as a result of needing a review by social service area team. If [by some freak chance] he was found to have capacity this would place him at an untenable risk. Everyone is working hard to make sure the new team fully understand the subtlety of his needs do not conform to the "standard". His parents [who are really supportive and terrified] insisted on being present with me for the assessment by the social worker. Outcome not known at this stage

3. Older female with ABI who needs a waking 24 hr package as a result of physical and cognitive disabilities. Has co-morbidities that places her at high risk of infections. Client has capacity but as she increases with age struggles with concentration especially on complex matters. When she has an infection she [like many older people] becomes confused, disoriented, stressed and angry Son [who has never taken part in her care other to complain about the adaptations to her home] is now stating that she cannot make her own decisions. Son utterly fails to understand her brain injury. As she is independently wealthy, the management of her funds may be of interest.
[NB EPA is dormant & with her solicitor as per her instructions!]

4. Older man with LD was assessed as retaining capacity during the development of a severe depressive episode. On admission to hospital he was diagnosed with a severe depressive episode and moderately severe frontal dementia. He was determined by the mental health team not to have capacity. On discharge to a care home where he has recovered and is happy, settled and able to clearly make a range of choices, accurate observations about his environment etc etc it would appear that the home have not been informed whether he remains a patient. They had not been informed of the capacity issue by the mental health team and were unable to confirm their intentions to establish the situation.
[NB claim still active and therefore outcome not yet known]

Capacity is such a thorny issue. It is hard for members of the general public to understand how it fluctuates and how we as case managers promote decision making and independence to support quality of life within an environment where the boundaries constantly shift. It has also been reported to me by a defendant solicitor that what they are seeing more frequently is the less severe injuries are often determined as not having capacity in order to obtain costs for a deputy. Their suspicion is that once the case has settled the issue of capacity is challenged, reversed and the client has more money than was necessary. I did point out that the reverse is true too!

Case Manager, Nurse, Midlands

To Whom It May Concern

Re: Mental Capacity Act 2005 and Acquired Brain Injury

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
I am a Brain Injury Case Manager, and I have been working in this role since 1993. In this time I have assessed and/or supported many individuals affected by physical, cognitive, emotional and psychological effects of acquired brain injury, as well as developed knowledge of other clients through clinical conversations with my colleagues.

As a Case Manager, I work closely with my clients enabling them to develop trust in me, and they often confide information to their Case Manager that they will tell few other people. I have access to confidential information about them and often gain intimate knowledge of how they live their lives; our company usually works with clients over a protracted length of time so that we develop an in-depth understanding of how their brain injury affects them and how they deal with situations, as well as developing an insight into how the lifestyle they create compares to their own hopes and expectations.

Since the Mental Capacity Act was revised in 2005 I have observed that it seems that Capacity Assessments carried out on our clients are more frequently either inconclusive or finding the client to have capacity than previously. It seems that clients who have a good residual intellect, who present plausibly and articulate their thoughts well are very likely to be considered to have capacity to manage their own affairs, even despite a lengthy history of impulsivity, lack of social judgement, tangential thought processes, problems with attention and a lack of insight into how their cognitive deficits affect their decision making. Yet this is a client group who can still be extremely vulnerable to malign influence and coercion, particularly if they are in possession of a lump sum of money.

The vulnerability of this client group is not easily seen during a one-off interview, when they will seem able to consider all relevant issues as asked (the questions themselves acting as a structure to prompt client’s consideration of issues, yet these same issues are not recognised in daily life); and will give thoughtful answers (because of the context of the interview, as opposed to a situation when they may be faced with choices that cue impulsivity, cause indecisiveness or present social pressures). Intellectually they are able to consider issues when presented with these issues as intellectual ideas; however when dealing with real life situations, many other pressures come to bear upon their decision making, causing them to make choices that may well not be commensurate with their actual personal values. Thus they may create lifestyles that are not truly of their choosing and not be able to escape this; yet the individual choices they make are seen as “an individual’s prerogative to make unwise choices”-ie: they are seen to be making lifestyle choices as opposed to suffering the results of the symptoms of a clinical condition.

In our work we sometimes see Social Workers assessing clients to have capacity without taking account of reports from treating clinicians, and without understanding how the assessment process impacts upon a client’s ability to function, ie: prompting the client to consider issues that they do not recognise when manifested in daily life. It seems that Social Workers are considered to be able to assess a brain injured client’s capacity even if they have no clinical knowledge of brain injury, yet the impact of brain injury upon an individual’s decision making ability is a specialist area of knowledge with effects that are both subtle and far

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
reaching. Once a client is found to have capacity, it causes an enormous upset and disruption to the therapeutic relationship if the Case Manager contests this decision.

It is my opinion that the knowledge area of brain injured individuals' capacity to make decisions needs to be acknowledged as a separate, speciality area. Laws and policies intended to protect these individuals can only achieve this end if they are created from a full understanding of brain injury, and an understanding of how it is distinct from other organic or psychiatric conditions that may also affect individuals' abilities to make decisions. I welcome this review and look forward to the development of greater understanding of my clients' needs.

Mental Capacity Act in practice

I have an example of a brain injured person who did not appear to have his capacity assessed when giving evidence at a trial, with serious consequences.

The client, a 60 year old man with an acquired brain injury, receives care via an agency.

He is deemed as not having capacity to manage his overall financial affairs, and therefore has a financial Deputy. However he is deemed to have capacity to manage his day to day finances for shopping and activities. The Deputy transfers money to his account, which he then manages.

It came to light that the agency carer appeared to be withdrawing money from the client's account over a particular period of about 3 months, using his debit card, amounting to several thousands of pounds. She was suspended and a police investigation ensued. All involved felt there was clear evidence of the fraud, as there was significant change in the activity on the client's bank account, with regular, large withdrawals being made.

The case went to the Magistrate's Court, and was referred to the Crown Court, due to the potential seriousness of the offence.

When the case went to trial, the brain injured client insisted on appearing in court, and was questioned for 1 ½ hours, after two days with 6am starts -not his normal daily routine. I understand his evidence was very confused, and he came across as not remembering the reasons for the withdrawals, which is due to his lack of insight and an impairment in his executive functioning. This is clear to those working closely and regularly with him. Despite evidence being given by the client's financial Deputy, and also by a long standing carer who knew his spending habits from of old, as well as (I believe) family members, the judge decided there was insufficient evidence to show that the client had not simply given the money to the carer. This had been her defence, and she was found not guilty.

Revealingly there was a further case involving the same carer this month, at a Magistrate's Court, in which she was found guilty of stealing £45 cash and £130 using a debit card from an 86 year old women for whom she was caring and cleaning. The

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carer was given a 12 week prison sentence suspended for 12 months -see attached newspaper report.

We are now waiting to see whether the case involving my former client (I no longer case manage him) will be reviewed, given there is now evidence of other fraudulent activity by this carer.

Lis Hough
Anglia Case Management
31st July 2013

Carer sentenced for theft from elderly woman
Written by LIZZY BUCHAN

A CARER who stole from an elderly woman in her charge has been handed a suspended sentence after pleading guilty to theft and fraud offences.

Alexandra Leonor, of Churchill Court, in Newmarket, appeared at Ipswich Magistrates Court on Tuesday 9 July where she pleaded guilty to stealing £45 cash from the 86-year-old woman she was caring for between April 2 and 8 this year.

Leonor took the victim's debit card and withdrew £130 from her bank account and bought items worth over £190 for herself.

The 31-year-old also pleaded guilty to a charge of fraud in a position of trust as she acted as a carer and cleaner for the 86-year-old.

Police were initially contacted on April 13 after the victim noticed money was missing from a drawer and that her debit card was missing from her purse earlier in the month.

Initial enquiries by family members had revealed transactions on her card that could not be accounted for. Further extensive enquiries by police confirmed Leonor had made the transactions and she was subsequently charged.

For both offences she was given a 12 week prison sentence suspended for 12 months. She was also ordered to pay over £360 compensation to her victim, £85 costs and an £80 victim surcharge.

Sgt Keith Grant, of Suffolk Constabulary, said: "She took advantage of the lady she was supposed to be caring for and stole from her, breaking her trust in a deplorable way.

"In initial interviews with police she denied committing the offences and tried to explain away her behaviour however following detailed enquiries officers managed to obtain overwhelming evidence against her, leading to the guilty plea."

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
My experience of the Mental Capacity Act applied to Brain Injured clients

Local Authority Social Workers tend to want to "own" the issue of capacity despite being non-specialists in brain injury. In a recent case, the Social Worker was sent a capacity Assessment, which had been carried out within the previous 2 months by an independent Consultant Neuropsychologist. However she informed the family that she had not even read the professor's assessment as her view should take precedence. The Social Worker then interviewed the client alone, using the Local Authority standard capacity assessment form and found that the client had capacity to make his own welfare decisions, which was counter to the findings of the Neuropsychologist, as well as the views of his family, four carers, and two case managers who were all closely involved in his care, and none of whom were consulted. Incidentally a Court Of Protection visitor also disagreed with the social workers assessment of his capacity (they had been instructed by the Court to undertake a routine visit but on finding that there were safeguarding issues against the client's brother, had undertaken a more detailed report for the Court. At present the safeguarding investigation is still ongoing.)

If the client is found by the Local Authority to have capacity, then empowering the client to exercise their human rights tends to be promoted over the services' Duty of care to the client. In my client's case the Local Authority social worker who met the client for the second time after he had been moved to temporary accommodation by the case manager, noted that my client had changed his mind since the last time they had met regarding a decision he was making. In this case the decision to change care provider, which would have resulted in the breakdown of his whole 24hr care regime. My client explained to her that when they had met previously, his brother, who had "secretly" moved into the client's home, and was present at the meeting (and against whom there is a current safeguarding investigation regarding psychological and financial abuse of my client) had told the client what he must say before the social worker arrived. By telling her this, my client gave a clear example of how vulnerable to suggestion he is and therefore unable to make a decision since he is so influenced by others, even those whom actions do not support his best interests. However the social worker still concluded from her assessment using the standard Local Authority form that he had capacity to make welfare decisions.

(In this case my client is currently protected by other family members, but in another case at Head First, the Local Authority found that a very vulnerable client who had sustained 2 brain injuries and was heavily influenced by her boyfriend, had capacity and was simply making a "lifestyle choice" to partake in street prostitution to fund both their drug habits.)

Other points:
• Assumption that families will be working in the best interest of the brain injured client, although we have found this is not always the case.
• Lack of understanding, particularly Local Authority Social workers, of the deficits most brain injured clients have, which affect their ability to make decisions - "CAPACITY" (including insight, impulsivity, ability to assess risk,

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
British Association of Brain Injury Case Managers – Written evidence

weigh up and judge options, remember, problem solve, etc) as well as impacting on their ability to follow through with any decision - "CAPABILITY?" (initiation/ memory/insight/ self-monitoring/ etc).

• The above point combined with the seeming unwillingness of many LA’s to work in partnership/consult and accept information from independent specialists/ can lead to brain injured clients being placed at risk.

In my view there should be a specific protocol for applying the MCA to people with brain injuries to try and reduce these risks.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Dear Jackie

I have not specifically highlighted any individual cases but have made comment based on many cases that I have witnessed and I have highlighted what I consider to have seen as the main recurring concerns and the questions this has raised.

My experience of those undertaking Mental Capacity Assessment for individuals with Acquired Brain Injury is that key cognitive factors and/or executive functioning are not taken into account and often one off assessment without any follow up to check on the individuals processing, understanding etc and what they remember are not carried out at all, let alone inline with an individual particular deficits in mind. In such cases I would consider a one off assessment to be inadequate and follow up meetings/assessments to be essential.

In addition to this, aspects around impulsivity are not considered and given the assessors requirement to make an assessment of the individuals ability to make the decision at “the time the decision needs to be made” I would also consider taking impulsivity into account.

I have also witnessed health care professional were the focus on the individuals right to make their own decision has not been balanced with an equal understanding of their duty to protect the individual and I question the level of training and/or competency level that is required to undertake mental capacity assessment given the serious nature and outcomes of bad decision making by the assessor.

Often I have seen cases whereby following an assessment when it has been deemed the individual does not have capacity that a decision is made on the behalf of the individual without consideration to a best interest meeting.

In summary, my experiences of some professional who undertake MCA of individuals with ABI has led me to question the following:

1) Can it be a fair/just and balanced process if the assessing professional does not have any knowledge of or a level of understanding of ABI?

2) Can it be a fair/just and balanced process if the assessing professional has not taken the time to make an assessment that includes talking to involved professional and family/friends who know the individual and/or accessing reading and understanding the relevant documentation/reports so that they, the assessor have a good understanding of the needs of the individual they are assessing.

3) Would we have a better fair/just and balanced process if it was essential for assessing professional to evidence their knowledge and the gathering of and utilisation of relevant background information to provide as part of the assessment process.

4) Would a closer link or comment on how the assessors decision safeguards the individual aid to a more thorough process.

5) Should an accredited/recognised level of training and/or competency level be required to undertake mental capacity assessment given the serious nature of the potential outcomes.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
I very much doubt I am raising comments and/or questions that have not been raised by others, but I hope my comments are helpful.

Kind regards

Iain Anderson  
Brain injury Case Manager  
Head First
The Committee on the Mental Capacity Act  
House of Lords  
London  
SW1A 0PW

22nd August 2013

Dear Sirs,

We are aware that the Committee on the Mental Capacity Act has called for evidence from professionals working in the field of brain injury with first hand experience of the Act in practice. We respond on behalf of JS Parker Limited.

JS Parker Limited is a case management and rehabilitation organisation. It is one of the largest specialist case management organisations with offices in Sheffield, Manchester, Edinburgh and North East of England. The majority of our clients have a range of brain and/or spinal injuries which result in physical, cognitive and behavioural problems.

As a company we work hard to ensure the Mental Capacity Act is used appropriately within our practice and work with our client group. We provide training for our all our specialist Case Managers and Support Workers to ensure the Act is used in every aspect of our day to day work with our clients.

Our clients with brain injury have complex cognitive problems these include -

- Lack of insight into their difficulties
- They are easily influenced and often say what they feel others want to hear.
- They can be impulsive and act without thinking through the consequences of an action or decision
- Very rigid and inflexible thinking
- Poor problem solving skills
- Reduced skills in reasoning
- Problems with planning and organisation of even simple or routine
- Reduced speed and capacity for processing information

Our experience of where the Act falls short is where our clients have interactions with professionals or staff with little or no understanding of the consequences of their brain injury.

They are a vulnerable group who are very often misunderstood and the Act can easily be misapplied in circumstances when used or indeed not applied by non specialist or inexperienced individuals.

We are able to provide further anecdotal evidence if this is helpful and would be happy to discuss our work and experiences in more detail if required.

Yours sincerely,

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
British Association of Social Workers – Written evidence

Submission by the British Association of Social Workers - Summary

1. BASW members are front line practitioners, operational managers, and independent social workers acting as Best Interest Assessors and Approved Mental Health Professionals.

2. The MCA is a vital piece of legislation in the provision of human rights of periodically or permanently incapacitated adults, & as of a consequence may be at greater risk of abuse and/or willful harm. Awareness of the MCA among professionals is poor; there is little understanding of the practice necessities of the Act and sometimes, there is a blatant disregard of the MCA.

3. In our view, the MCA has achieved its aim of providing a legal framework for protecting individuals who cannot make some decisions for themselves. With regards to adult safeguarding, there is the need to be more explicit about the scope and powers of local authorities (or professionals). Clearer guidance from the Code of Practice on the interplay between adult safeguarding and mental capacity in the face of recent COP judgments is needed.

4. Both the MCA & DoLS Codes of Practice need to be revised & merged into one to reflect recent case law, as it is apparent that they are now inaccurate in light of recent court judgments. Furthermore there is the need for greater clarity on “significant decisions” and what cases “must” be brought to COP. The tensions between care/control in safeguarding could also be resolved through more explanations of the powers of local authorities in best interest deliberations.

5. The implementation of the MCA has been “variable”. Our members felt that the increasing emphasis on multi-disciplinary work should be accompanied by multi-professional training in the MCA so that agencies can be more informed of their duties and responsibilities under the Act and their staff trained accordingly.

6. The scope of provision of IMCA services should be expanded. The statutory criteria for IMCA provision are very narrow and this reduces their overall effectiveness to service users and patients.

7. BASW members consider that the Deprivation of Liberty Safeguards (DoLS) work well where properly applied. But as with the Act as a whole, there is a lack of awareness of DoLS. The greatest need is to still empower & ensure care providers reduce restrictions & restraints being used on service users.

8. Two legislative amendments were suggested as viable substitutes for DoLS: (a) A revised Section 7 of the Mental Health Act (MHA) as a simpler way of authorising any necessary detentions in care homes and similar settings. (b) A new form of Guardianship under the Mental Capacity Act, with a more accessible tribunal system for appeals and mandatory periodic reviews of detentions.

9. BASW recognises that the Care Quality Commission (CQC) can make a significant difference in MCA awareness and compliance by statutory services. CQC

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should be given regulatory powers in this regard because supervisory bodies are central to the discharge of legal responsibilities under DoLS.

10. Our members see the Court of Protection as often costly, bureaucratic, and lacking transparency/openness in how it conducts its business.

11. There seems to be little publicised guidelines for Relevant Person’s Representatives (RPR) in their role as Litigation Friend. Furthermore how an RPR obtains independent legal advice & of access to public funding for this is unclear.

12. BASW members expressed their concerns that there is a knowledge gap regarding the interplay between the MCA (including DoLS) and MHA. There are also issues pertinent to local authorities on the border between England and Wales.

Submission by the British Association of Social Workers.

1. The British Association of Social Workers (BASW) recognises the unique opportunity to contribute to this influential inquiry. Members of BASW’s Mental Health Reference Group work across statutory and independent sectors in health and social care, and as such, are in unique position to provide the Select Committee with a range of views and experiences of the MCA. BASW members are front line practitioners, operational managers, and independent social workers acting as Best Interest Assessors and Approved Mental Health Professionals. In these various roles members have also provided training in the MCA to different professionals and have been responsible for local implementation of the Act in localities across England.

2. There are two clear and consistent messages that our members inform us: That the MCA is a vital piece of legislation in the provision of human rights of periodically or permanently incapacitated adults, & as of a consequence may be at greater risk of abuse and/or willful harm. The MCA requires families, neighbours, informal carers, and health and social care professionals to be mindful of a vulnerable citizens’ rights and that they should be at the centre of all decisions about their care and treatment. The fundamental values and principles of the MCA strongly support the ethos of person centered care planning. Through the ‘best interest’ principle the Act provides a coherent statutory framework to underpin the intentions and actions of those caring for incapacitated adults.

3. The second key message from BASW members is that awareness of the MCA among professionals is poor; there is little understanding of the practice necessities of the Act and sometimes, there is a blatant disregard of the MCA. Furthermore although there are voluminous amounts of information about the MCA, there is the need to make it less technical and more specific to discrete groups of professionals. For service users and carers it is imperative that the guidance and information is made more meaningful to their circumstances: as well as informing people of their rights This will also empower them to challenge bad practice.

Overview and Context

4. In our view, the MCA has achieved its aim of providing a legal framework for protecting individuals who cannot make some decisions for themselves. The Act sets

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out a clear decision-making process and in addition to the underlying principle of always assuming a person has capacity, stipulates that where a person does not have capacity for specific decisions, they participate as much as possible in any decisions made on their behalf, and that these are made in their best interests. However, we consider that there is a problem with implementation; this view is captured by this quote from one of our members “The problem is not the Act but one of implementation and embedding the changes as this can be seen to be patchy even in statutory services let alone in care homes and individual family carers”.

5. Our members acknowledge that the amendment to the MCA, the Deprivation of Liberty Safeguards can in practice be “overly bureaucratic, voluminous and achieving minimal increase in the rights of the people it was designed to protect”. We also note that from the recent figures published by the Health & Social Care Information Centre, that there continues to be a year on year increase in the number of applications completed for DoLS since the introduction 2009/10, with 55% being authorized. This being contrary to predictions by the Department of Health that applications would fall at a constant between 2009/10 & 2015/16. Such may inform encouraging signs that closer scrutiny is being applied as to the requirement & proportionality of restrictions being used on an incapacitated person.

6. In addition we have observed encouraging signs that service providers are placing greater efforts on alternatives to restrictions under DoLS by providing for example different activities and changes in care environments. Providers are thinking more carefully about whether it is imperative that they draw on the DoLS powers.

7. Our members have also witnessed instances such as in safeguarding cases where the Act has been used negatively to increase statutory power in decision-making. We believe that these practices contradict the principles underpinning the MCA

8. BASW members felt strongly that the two separate codes of practice that accompany the MCA need revision to provide greater clarity. Due to evolving case law, the two Codes of Practice are outdated. It is a well-rehearsed argument among practitioners, academics, lawyers, and advocacy groups that the distinction between deprivation and restriction of liberty is ambiguous, such that further guidance will be helpful. Furthermore, we have noted for instance that the Court of Protection (COP) has held that previous tests of capacity stand and should be used alongside the MCA’s two-stage capacity test whereas the MCA Code of Practice maintains that past assessments should not influence the current. This contradiction has created uncertainty around one of the key planks of the MCA, hence statutory direction is needed as to which view holds in practice. Keeping to capacity assessments, practitioners will find it helpful if further guidance is provided on where the "other" statutory capacity tests stand alongside the two-stage tests – for example in terms of testimonial capacity, litigation capacity, capacity for sex/marriage etc. There should also be additional advice on who should be involved in such tests of capacity and in what circumstances.

9. Equally importantly, as frontline practitioners, our members would find it helpful if the two Codes were merged. Arguably the supplementary Code was necessary because of the subsequent Bournewood judgment, noting also that the

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DoLS Code of Practice anticipates that revision will be required as case law emerges. That time has now come.

10. We suggest clearer guidance from the Code of Practice on the interplay between adult safeguarding and mental capacity in the face of recent COP judgments. BASW members are particularly mindful of Judge Munby’s criticism of authorities exceeding their powers in areas that require the jurisdiction of the court. But in some instances such as in welfare cases there could be unresolvable dispute with families or patients. Furthermore the Munby judgment footnoted above suggests that where there are safeguarding concerns, and professionals assess that it is in service users’ best interest, they cannot draw on the MCA to justify restricting contact between them and others, nor can they move a vulnerable adult to a place of safety against the wishes of their family. In the face of the Munby judgment, without further clarification in a form of guidance on the care/control tension inherent in safeguarding, it is likely that professionals will be seen as disempowering and over reactive by judges & indeed the public. We acknowledge that professionals, service providers, and local authorities need to be held to account for malpractice; however more lucidity in a revised Code of Practice will greatly resolve some of the tensions in safeguarding incapacitated adults.

11. With further regards to adult safeguarding, there is the need to be more explicit about the scope and powers of local authorities (or professionals). Our members have noted that the Court of Protection has interpreted the Code of Practice differently from the Act per se. The Code explicitly informs that where professionals are decision makers in best interest deliberations, they are required to listen to all views and then arrive at a decision. To date however many cases have come to the Court of Protection in which local authorities (in most cases as lead agencies for adult safeguarding) have considered that they have limited powers to make these decisions.

12. There have been some COP judgments that if there is an unresolvable issue with family or incapacitated adult on a “significant matter” it cannot be made by a decision maker under the MCA it has to be settled in Court. However there is no explanation of “significant decisions”, consequently, it is likely that more cases will be referred to COP. It is a reasonable expectation for instance that where professionals wish to move an incapacitated service user to different accommodation and this is opposed by family members or vice versa, it should be referred to COP. However there are many other cases that, in the view of BASW, which do not require COP’s consideration. Better guidance on the meaning of “significant decisions” will help build consensus between professionals and families of incapacitated adults, and may also lead to less referrals to COP which can delay care planning.

13. Following on from the previous point, there is the need for better mediation services. It is noted that parties involved in the care of incapacitated adults sometime make “hasty” applications to COP instead of considering independent mediation. There are indications that mediation services are less costly than COP hearings and cases can be dealt with more speedily. Besides, mediation can encourage consensus between parties involved in the care of the incapacitated adult.
14. In summary both the MCA & DoLS Codes of Practice need to be revised & merged into one to reflect recent case law, as it is apparent that they are now inaccurate in light of recent court judgments. Furthermore there is the need for greater clarity on “significant decisions” and what cases “must” be brought to COP. The tensions between care/control in safeguarding could also be resolved through more explanations of the powers of local authorities in best interest deliberations.

Implementation

15. Members of BASW informed that implementation of the MCA has been “variable”. Some professionals reported that police officers and the ambulance service appeared slower off the mark in their implementation of the Act. In some cases of attempted suicide, and where paramedics had to convey patients to hospital, the MCA did not appear an important consideration. Some ambulance personnel appeared to make judgments about capacity without conducting the required two-stage test of capacity to inform their decision-making. Equally other professionals affiliated to BASW reported signs of increasing awareness “with fewer and fewer instances of ambulance paramedics refusing to escort people under the MCA without a “pink form” of authority as under the MHA…. but as with health and social services much work is still required to embed the Act in day to day practice”.

16. BASW members work in multi-disciplinary settings and report a general lack of awareness among some professions as to how the MCA is directly relevant & applicable to their work. Our members also provide training to other agencies and sometimes find it surprising that community based primary care staff employed in large NHS Trusts have only ‘vaguely’ heard of the MCA. Recently a BASW member conducted 25 half-day sessions with around 400 NHS staff including dentists, physiotherapists, podiatrists, district nurses, speech therapists, and health care assistants. For 60% of attendees this was their first ever training in the MCA.

17. Our members felt that the increasing emphasis on multi-disciplinary work should be accompanied by multi-professional training in the MCA so that agencies can be more informed of their duties and responsibilities under the Act and their staff trained accordingly. However concerns were also raised that there was limited funding available due to pressures on budgets. As one member commented “many of them [local authorities] did inform other agencies that they had multi agency funding [for training] which now seems to have vanished!”

18. Where mental health patients are admitted to hospital informally, it is not routine that their mental capacity is assessed if they ‘agree’ to remain in hospital. An informal admission is always considered a less restrictive option and therefore preferable. However some informal admissions become formal detentions raising questions about whether the person had capacity to agree to in the first place, with no written evidence of the required capacity assessment being made in the patient’s notes. Understandably people who are subsequently formally detained may feel “betrayed” as they did not know what they "were walking into".

18. BASW members report that many psychiatric hospitals have their ‘own procedures’ pertaining to the assessment of capacity of detained patients. Not all hospitals record assessments at the appropriate times – for example whether in treatment reviews or renewal of detention. Additionally there seems to be a range

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of ways of recording - from a brief note on file to a designated preforma - how the assessment of capacity was undertaken or in demonstrating ‘their workings out’ in accordance with the application of the Five Principles of the MCA.

Decision Making

19. Some professionals erroneously believe that decisions arrived ‘collectively’, say by a multi-disciplinary team and can override family or service user’s views if they follow the correct MCA processes and act in a way they think is their service user’s best interests.

20. In terms of assessment of decision-making capacity it is sometimes assumed that only professionals can do such work, and family members are sidelined. It is not always apparent to professionals that “those who know the person best” also refers to family members or close friends and not necessarily colleagues.

21. Professionals sometimes implement the MCA informally. As an illustration, some professionals will claim to be acting in the best interests of patients and service users when in fact they have not completed formal best interest checklist so they cannot demonstrate that they have followed the stipulations of the MCA. In addition very few best interest ‘risk balance sheets’ or ‘wishes and feelings’ checklists are being used probably due to failure to formally incorporate these into local policies and practices. Added to these, professionals are sometimes under time pressures; therefore they neglect the formal aspects of the Act such as completion of requisite forms. We note in particular the pressures placed on acute hospitals by persons once referred to as a ‘patient’, being re-designated as a ‘bed blocker’ & the responsibility for discharge being placed on the Local Authority if they are not to occur a financial penalty. The application of the MCA faces a stiff challenge in such circumstances!

22. Families and patients are sometimes excluded from professional discussions at best interest meetings and are often invited in at the end when the decisions about have been made.

23. The scope of provision of IMCA services should be expanded. IMCAs have a good reputation and their reports on best interest decisions are respected. However the statutory criteria for IMCA provision are very narrow and this reduces their overall effectiveness to service users and patients. The IMCA criteria should be broadened to allow greater discretion around their use in a wider range of appropriate circumstances. This is especially needed where there is conflict between family and professionals around best interest but there are no safeguarding concerns (at present this will exclude the commissioning of IMCA services). This is not to facilitate mediation between parties but to provide the benefit of an independent assessment.

Deprivation of Liberty Safeguards

24. BASW members consider that the Deprivation of Liberty Safeguards (DoLS) work well where properly applied. But as with the Act as a whole, there is a lack of awareness of DoLS, & as the recent annual informatics review informs, some considerable variations in delivery across some local services. There are real

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practical difficulties in operationalising aspects of DoLS, largely informed by the lack of a clear definition of a Deprivation of Liberty. This coupled by some authorities applying their own ‘interpretation’ of CoP judgments to local cases in disregard to the specific & individual circumstances noted in the original case judgement. We should now be in a position where a clear definition can & should be made and to bring clarity to new guidance required in the Code of Practice.

25. The greatest need is to still empower & ensure care providers reduce restrictions & restraints being used on service users. We acknowledge that CQC, NICE, SCIE & care home organisations continue to encourage care home providers in reducing the use of such. Person centered planning is in the first instance about reducing the need for the use of restraint &/or restriction. In not undertaking such often can lead to a ‘hasty’ DOLS referral being made. Benefits of refraining from restraint use have been well documented and include improvement in quality of life, greater autonomy, reduction in use of anti-psychotic medications, less skin breakdown and a reduction in seriousness of injuries due to falls. A person-centered environment is a restraint free environment.

26. Professionals affiliated to BASW have also noted the ongoing debates about whether DoLS should be repealed or amended, and reasons for the countrywide variations in DoLS authorisations. Some members argue that DoLS should be retained while others call for it to be replaced. Two legislative amendments were suggested as viable substitutes for DoLS: 1) A revised Section 7 of the Mental Health Act (MHA) as a simpler way of authorising any necessary detentions in care homes and similar settings. However it is also recognised the potential consequence of this first suggestion is the conflation of mental health and mental capacity. 2) A new form of Guardianship under the Mental Capacity Act, with a more accessible tribunal system for appeals and mandatory periodic reviews of detentions.

27. At the same time our members do not want the debate about the differences in DoLS authorisations to center on quantitative analysis because the statistics reveal little about the quality of the assessments on one hand, and the decisions leading to authorisations on the other. Consequently BASW calls for further qualitative syntheses to better understand the strengths and weaknesses of local practices instead of undue focus on numbers.

BASW notes that in some areas the length of DOLS authorisations is becoming shorter. We believe that this positive development has been, in part, influenced by Best Interest Assessors deliberately keeping the focus and pressure on service providers to draw up care plans that minimise restrictions as much as possible for service users.

The Court of Protection and the Office of the Public Guardian

28. Our members see the Court of Protection as often costly, bureaucratic, and lacking transparency/openness in how it conducts its business. Given the volume of work that the court is required to deal with there can be a considerable delay in the case being considered by the Court. We note however that access is available in circumstances that require urgent consideration by the Court. Some practitioners think that consideration should be given to the use of a First Tier Tribunal system for reviewing some MCA cases.

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29. BASW members gave their views on the reasons for the relatively high cost of COP cases. One of these may be down to the stipulation that only barristers can represent cases, meaning that local authority solicitors who are less costly cannot address Judges directly. Added to this, there is the tendency to routinely commission independent psychiatric and social work reports – besides financial costs, this can also prolong cases. Also funding the costs of the Official Solicitor, who in turn also instructs barristers to carry out its role, is also expensive.

30. The current eligibility criteria for accessing legal aid arguably restrict how many people can be represented in the Court. An illuminating example is that of informal care. If a foster carer has looked after someone since childhood but they now care for them informally in adulthood and they become incapacitated, were an NHS Trust or local authority to apply to the Court in matters regarding the incapacitated adult, then the carer would not qualify for legal aid because their care arrangement is informal!

31. There seems to be little publicised guidelines for Relevant Person’s Representatives (RPR) in their role as Litigation Friend. The judgment in AB v LCC (a Local Authority) [2011] EWHC 3151 allows the Relevant Person’s Representative (RPR) in a Section 21A appeal against a DoLS authorisation to act as Litigation Friend of the protected party instead of the Official Solicitor. Other than this judgment, there are no guidelines developed for RPRs in their role as Litigation Friend. It may not have been anticipated in the IMCA/RPR contract with the Local Authority that they would play such a role, nevertheless, the court case cited here means that RPRs can have dual roles. Therefore there is the need for additional guidance.

32. Furthermore how an RPR obtains independent legal advice & of access to public funding for this is unclear, as there appears to be no specific guidance from the Legal Aid Agency, the Courts or the Department of Health. It would therefore be helpful if a list of specialist COP solicitors in various regions that are prepared to advise and act as legal representatives of RPRs could be drawn up, as well as funding eligibility to be considered.

33. Lasting Powers of Attorney (LPA): BASW members reported that the numbers and validity of LPAs for health and welfare are considerably lower in comparison to finance and property. We suggest that there should be increased awareness of health and welfare LPAs, as they should inform that the required consultation has taken place with the person making the application to determine their ‘best interests ‘ & wishes prior to the time when they may become incapacitated. This is an effective way of shifting the balance of power in decision-making, and of informing a cultural change in social care practice though enabling individual responsibility & self-determination.

34. BASW members wish to note that their approval that the fee exemptions for registering for LPAs have remained for those on low pay or in receipt of welfare benefits.

Regulation

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35. BASW recognises that the Care Quality Commission (CQC) can make a significant difference in MCA awareness and compliance by statutory services. We note that the (CQC) aims in its 2013-16 strategic plans to strengthen its regulation of MCA (and the MHA) practice with a significant investment in MCA expertise. However this may be hindered because CQC does not have specific standards relevant to the day-to-day operational requirements of the MCA. We strongly recommend that consideration be given to enable the CQC to have the same effective powers with the MCA as it has with the MHA.

36. In addition we note that the CQC has no powers to regulate local authority supervisory bodies under DoLS and depends instead on their “co-operation”. CQC should be given regulatory powers in this regard because supervisory bodies are central to the discharge of legal responsibilities under DoLS.

Other Legislation

37. BASW members expressed their concerns that there is a knowledge gap regarding the interplay between the MCA (including DoLS) and MHA. Members reported that the relationship and tensions between these important pieces of legislation are poorly understood; therefore, there is the need for more accessible and non-technical guidance for frontline practitioners.

38. BASW wishes the Select Committee to note that recent developments could further erode the knowledge base of MCA and MHA practice. Firstly, there are concerns about the disintegration agenda in some mental health services as evidenced by our recent audit of the breaking up of a number of multi-disciplinary adult social care and mental health teams in parts of England. Disintegration will lead to the loss of valuable expertise in the overlaps between the MCA and MHA. Secondly, our members have noticed that experienced practitioners, including advisory specialists, are not replaced when they retire. If DoLS and MHA are aimed at protecting human rights of incapacitated adults, then this goal is placed at severe risk by the absence of front line expertise.

Devolved administrations and International Context

39. There are issues pertinent to local authorities on the border between England and Wales. Cross-border differential recognition of Best Interest Assessments in Wales/England is an issue where peoples’ home addresses, care home addresses, hospital addresses, informal carers’ addresses and GP surgery address fall on either side of the border in any combination.

40. The Act and guidance assume that people conduct all their affairs in one jurisdiction or make a single, one-off and complete move across the border but this is not always the case.

30th August 2013
British Association of Social Workers and The College of Social Work – Oral evidence (QQ 139 – 152)

Evidence Session No. 7 Heard in Public Questions 139 - 152

TUESDAY 8 OCTOBER 2013

Members present

Lord Hardie (Chairman)
Baroness Andrews
Baroness Barker
Baroness Browning
Lord Faulks
Baroness Hollins
Baroness McIntosh of Hudnall
Lord Patel of Bradford
Lord Swinfen
Lord Turnberg

Examination of Witnesses

Anna Ribas Gonzalez and Robert Nisbet, British Association of Social Workers, and Dr Ruth Allen, Chair of the Mental Health Faculty, the College of Social Work

Q139 The Chairman: Good morning. Welcome to this session of the Select Committee on the Mental Capacity Act. I am grateful to you for attending as witnesses and also for your detailed written submissions, which have been extremely helpful to the Committee. You will appreciate, from the evidence and from your own submissions, that there are questions about widespread non-compliance with the Mental Capacity Act, and the first two written questions, which have been submitted to you, really relate to that, but they have been divided into two parts, dealing in the first instance with social workers themselves and then the second one deals with others. Could I ask, particularly under reference to the College of Social Work, what you consider to be the reasons for non-compliance by social workers with the Act and what solutions you propose?

Dr Allen: The evidence for non-compliance is coming from quite a lot of different quarters. There is case law, there are reports from CQC, and then there is the review that we have done through our own members, in seeking their views. There

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is evidence there. A lot of the decisions around mental capacity are not always totally transparent. There are no standardised forms to fill in, apart from in relation to Deprivation of Liberty Safeguards. That is clearly documented. There is something too loose about the implementation of the Mental Capacity Act: it is a vital bit of legislation; very important decisions are being made; and the monitoring of that is being left very much to local arrangements. It is through a lack of accountability for employing responsible agencies, whether that is the NHS or local authorities, on all of the types of Mental Capacity Act decisions that have to be made that we see this risk and the actuality of non-compliance. There is something about the way the MCA is regulated, monitored and the governance around it that is weak. If you compare it to the Mental Health Act, for instance, it is considerably weaker. In terms of what happens with the workforce, in terms of social work which I am here to represent, there are issues about training and development. Social work is a profession under pressure at the moment, as we know. All professions in health and care are under a lot of pressure. There is a challenge to maintain the quality and standards of practice. Some very fine decision-making has a profound impact on people’s lives. How do we ensure that quality of practice is being promoted in every local authority, every NHS body that is hosting social workers and every other agency that is managing social workers? There is something about training and ongoing development of staff.

Another key issue is that, as the Act has been implemented, we have perhaps underestimated the degree to which this is a cultural and attitudinal shift in the relationship between all professionals and the people that they serve. It is a societal challenge about how we promote enablement, people’s autonomy and rights, across professions, including social work—although I would like to think social work is really changing in this respect—but all professions come from quite a paternalistic position. The MCA is not yet fully understood across any profession as an enabling piece of legislation about protecting people’s rights to choose, primarily, and it is often seen as bolstering the desire to protect and, in some ways, control people’s choice-making. That is still a cultural and attitudinal problem.

Q140 The Chairman: Could I ask all three of you how you think social workers are equipped to undertake assessments of capacity for the purposes of the Act, irrespective of the nature of the person’s impairment? For instance, there is some evidence about brain-injury cases; there is some suggestion that social workers are not particularly equipped to make that assessment. Perhaps the Association of Social Workers would like to lead on that.

Anna Ribas Gonzalez: It is certain that, with certain individuals, social workers might not feel equipped to that, but they do not have to do it in isolation. The intention is for people to seek help from other professionals, who might be in a better position to understand the illness of the patient or the situation of the patient. We agree with many aspects of what my colleague from the College of Social Work has said, and we pointed that out in our submission paper.

We do feel that the culture is changing, mainly in the social-work context, but we find, in many situations, such as in acute hospitals and care homes, there are other professionals, from social care settings or from social care and health professions, who do not feel confident in carrying out capacity assessments. Sometimes, or in
many circumstances, mental health services are asked to intervene because of that lack of confidence and probably expertise in doing so. Definitely there is a need for more specific and hands-on training into carrying out assessments and real-life situations.

**The Chairman:** The second issue really is related to that. The first one was concerned with social workers themselves. The majority of the submissions that criticise non-compliance concentrate on non-compliance by other professionals in the social work context. Could I ask you first of all what evidence you have for that non-compliance and what solutions you propose for it?

**Robert Nisbet:** I would like to think that it is also, rather than just half-empty, a half-full glass. Yes, there is evidence of non-compliance, but there is also considerable evidence around services, agencies and professions really getting to grips with this. I do not want to portray us on a downward slope, as it were; I think we are on the up, but it does take time.

The areas of non-compliance that I have experienced are predominantly within frontline health professionals across primary care services—GPs, nursing, podiatry, dentists, etc. I am seeing quite a considerable amount of training with frontline primary care staff and, for many, it is their first time ever undertaking any formal training. What they have picked up on the Mental Capacity Act tends to be hearsay or anecdotal. That does not underlie their incredible motivation and willingness to apply the Mental Capacity Act. It is something that was just left to one side. An awful lot of effort went into care homes and social care staff, and we neglected many of our health colleagues or we assumed that it had been done. That is one area.

I also think that we are dealing with hierarchies and medical professions that tend to see that perhaps they have always or have largely been the decision-makers. The decision-making being moved to a number of other professions, individuals, etc, poses quite a lot of challenges. It poses challenges to those who have always been very used to “the doctor knows best”, or would refer to the consultant or the GP for that decision, compared to what is required of making that decision themselves, if they are the person who is dealing directly with that case and they have undertaken their assessment. We have a long way to go, but I do sense the beginnings of us turning the tide. I am more confident now that we have listening ears, rather than individuals or bodies who just say, “This doesn’t belong to us”, or “This isn’t to do with us”.

**Dr Allen:** I would agree with that. We do have a very long way to go. We probably ignored health colleagues in the early stages of implementation of the Act, and made assumptions that the principles could be logically grasped and that they would then turn into practice. Actually, that is not really how things happen; that is not how things get implemented. The sense of doing good for others, rather than doing with, is actually a fundamentally quite difficult concept for some health colleagues. I work in the NHS, so I work alongside doctors, nurses and all the other health staff on a day-to-day basis, so that is my own personal experience as well. The matter of other professions being deferential towards the decisions of doctors, with regard to matters of best interest, is an important one that needs to be addressed in training and in thinking about how to support implementation across professions.

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The College would take the position that social workers should have a lead role in relation to systems where the MCA is being implemented. This absolutely needs to be owned across all professions, but social workers should have absolute focus on best practice, knowledge and being able to share that knowledge with colleagues across the system, and having a leadership role in ensuring that people's rights and their right to have their autonomy and their choice-making optimised. That should be something on which social workers can lead.

**Q141 The Chairman:** Apart from the concerns about implementation by professionals, your submissions also raise concern about the application of the Act in family or informal caring settings. What evidence do you have of compliance in those settings?

**Robert Nisbet:** In terms of the hard evidence, Lord Chairman, I cannot call upon that in terms of considerable volumes of research. What I do pick up from families, particularly at times of crisis, when a relative is at the brink of perhaps being considered for going into a residential care home or there is another crisis within their care, to then be faced with someone saying, “We have to consider the Mental Capacity Act here, and best interest”, is a bewildering world for them. Quite rightly, they want to make decisions that they consider are in the best interest, without the amount of protocol and process they have to go through in relation to the Mental Capacity Act. It is quite bewildering for them.

We have not done very well in educating the public in respect to what the Mental Capacity Act is about, let alone what you can do about preparing for a time in your own lives when you may lose capacity. It just is not on the radar in relation to professionals, the media and what-have-you educating families as to what the Act is, and about their rights and responsibilities. There is a huge amount of misinformation; there is a huge amount of ignorance. I would like to feel that this is an Act that is wholly supportive of families and carers being integral to the best interests or care of their family members or relatives, but I also feel that, as professionals, we have a considerable amount of work to do to bring that across.

My final point is that there is a crisis of public confidence in many public-sector services, and there is certainly a crisis of the public's confidence in social work. Consequently, whether people have trust or confidence that social workers are able to involve families and communicate with family members as equals has, in some ways, come under considerable scrutiny and threat. We have a long way to go before I feel families can trust us and see us as equal partners in this.

**The Chairman:** Finally, could I ask you what sanctions exist for non-compliance? Do you consider that there should be more effective sanctions and, if so, what?

**Dr Allen:** I think through CQC regulatory scrutiny, certainly within the NHS context, we will see sanctions through that process in terms of the way non-compliance is picked up, for instance in relation to consent and capacity. That is one way in which it happens, and it has actually been very helpful within mental health organisations to have that reflected back by the CQC. That has been something that has raised the profile of the Mental Capacity Act with chief
executives for instance. That is really what you need to do: you need to get your director of adult social services, your chief executive or your other most senior executives to recognise the importance of this. There is something about those very senior leaders recognising that there is organisational risk in not complying. That organisational risk has not always come into enough focus for them actually, in these first few years of implementation. It is too easy not to do very well with the Mental Capacity Act at the moment. That is a key issue.

Q142 Baroness Browning: Could I ask you about the relationship between safeguarding and the Mental Capacity Act? Are social-work professionals under pressure to prioritise safeguarding, as opposed to fulfilling the broad principles of the Mental Capacity Act, which are about empowerment? When you answer that, I wonder if you could just tell us how that empowerment is achieved, when most of your packages will be delivered by third parties. Although social workers may well do assessments and may agree a package, the day-to-day delivery of that is most likely delivered by agency staff who, on a day-to-day basis, will actually be the people helping that person with decision-making, being the people on the ground who will see when circumstances are beginning to change.

Dr Allen: I absolutely think that safeguarding has taken precedence over the implementation of the Act in its fullest form. The protective impetus behind safeguarding has been a real driver in how adult social care over the last few years, and there is a lot that is very good about that. It has however been very proceduralised, and that has taken up a lot of time and energy. It has often been process-driven, rather than necessarily being driven by the outcomes for individuals, for instance, and their experience of that safeguarding process. That is beginning to change, but there is a journey yet to go on.

For individual social workers, many will feel that adult safeguarding is now very dominant in their working day. They will, at times, struggle, and may or may not have the right supervisory guidance in the matter of self-determination versus the sense of needing to act. Going back to the organisational-risk bit, the organisational risk in relation to adult safeguarding, and not acting and not being seen to act to protect, has a much higher profile than the organisational risk of not enabling and not providing people with the opportunity to pursue choice and so on.

What we are hearing more about now is how personalisation and safeguarding, in a sense, are two sides of the same coin. What you were describing was in terms of the social care processes of assessments being done, resources being made available and services then being provided. The intention of personalisation and self-directed support is moving much more towards how much people can take control over how that resource is used for them, by them, with whatever support, including with family support. That is what self-directed support and personalisation are—people may be using direct payments or not, but certainly having more control. There is something we need to improve in relation to how we work with people, whether they have full capacity to make those decisions or maybe they are partially impaired but can make other decisions. How do we work with as much capacity as a person has to make decisions that meet their needs, and also help to keep them safe? That process and practice is relatively easy to say, but actually it has been a very difficult transition in practice - to get that lined up so that, in all or most cases, you can say that that

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person has the most made of their capacity to make decisions. They have made some decisions that meet their needs and help them to feel safe. Our approach to safeguarding will be as light-touch as it needs to be, i.e. not overly intervening, but enough to make the difference that is needed to keep the person safe.

Q143 Baroness Browning: Could I just add here that there was some discussion when the Bill went through and when we had the pre-legislative scrutiny? Several of us in this room were on all three stages of the Bill, which is a nice thing to be able to do. There was quite a lot of discussion about the fact that people who lack capacity have the same right as everybody else to make the wrong decisions, from time to time. I just wonder how you deal with somebody quite evidently making a wrong decision in the context of safeguarding.

Robert Nisbet: Good point. My Lord Chairman, if I can just cover it, I agree with my colleague. I just want to add a couple of things and focus. For me, the whole rationale behind social work is that fine balance in upholding the rights of the individual and advocating on behalf of that person—particularly where that person is not able to undertake that themselves, through disability, incapacity or what-have-you—and at the same time, having a sense of responsibility and managing that risk where that person may not have that awareness and may be putting themselves or other people in danger. It is a very fine balance.

I can say that, for many reasons, we have veered towards risk-aversion, and by that I mean that we fear the blame. We fear that, if something goes wrong, we will be named or scrutinised. I use the expression, “The goalie’s fear of the penalty”. You do not want to be left holding it. It often comes down to safeguarding. I do not see safeguarding as separate from what is core and fundamental to social work. It is just what you do. It is about balancing those rights. When the Mental Capacity Act came along I thought, “Wow, we have at long last got a piece of sensible legislation that enables us to really look at how we uphold that balance.”

However, if it is that, say, we assess someone as having capacity for a specific decision and they are very likely to place themselves at serious risk—not others, but themselves—maybe in terms of a relationship or continuing a relationship that is physically abusive, who is going to be brave enough to say, “We respect that decision”? There is a fear of scrutiny because someone says, “They have a learning disability,” or, “They are a person who you were involved with”, and by implication it seems we should therefore resolve those problems. It is very difficult to stand up and say, “We have assessed this person. We may disagree with what they are doing, but it is their right, as it is my right, to make mistakes in their life and to make unwise decisions.” I have not seen many people able to do that. Organisations do not permit it, because they are very fearful of scrutiny and the media is very, very powerful, as we have seen over many years and certainly over the last few weeks. We veer towards overprotection and safeguarding, which sometimes undermines some of the very important principles behind the Act.

There is a lot that the Mental Capacity Act supports in enabling safeguarding to be competent, fair and just, but the chance to get it right or to do it properly—sometimes the rug is pulled from beneath us, and we are placed in a difficult position.

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Q144 Baroness Andrews: I just want to follow that up, in a way, because in this very clear evidence you have produced you do talk about the need to improve the codes of practice. At the same time, you point out—and we have heard this in other evidence—that there is huge variation on the ground. You have just described, Robert, the challenge to the individual practitioner. We come on to talk about culture later on, but how can a revised code of practice, when we know so much is left to local discretion, make any difference if, at the design and delivery point, both at the level of the local authority and the individual practitioner, it is not necessarily going to be observed?

Robert Nisbet: My Lord Chairman, I agree. We have a Highway Code, but it does not mean that everybody keeps to the speed limits. We know it is sensible to keep to speed limits, but we also somehow undermine them, or whatever. Maybe some do not. I agree; I do not have an answer, unfortunately. I wish I did.

Anna Ribas Gonzalez: Some of the clarifications that we mentioned about the Code of Practice also refer to the new case law that has come about, mainly decisions about accommodation, where some local authorities have decided not to take cases to the Court of Protection for several reasons. Some may be reasons of cost. Decisions have been made knowing that there are not going to be consequences. There has been a lot of recent case law showing us how to practise best. It would be good to provide that as guidance.

Baroness Andrews: My point essentially is that you would still like to see changes in the Code of Practice, despite the fact that there are difficulties.

Anna Ribas Gonzalez: It is also about describing more what “significant decisions” mean. That is what we were referring to in our submission. It is not about making a descriptive description about what it is, but some guidance about what exactly we mean, because “significant decision” means something different to me as it does to someone else.

Lord Swinfen: I was just wondering how well the social workers know those with limited capacity. What is the changeover? How long do they work with them? Do they really have the ability to judge the capacity of someone to make a particular decision?

Dr Allen: I think that is a very pertinent question. I was thinking about it on the way in, actually. In the matter of, for instance, making what appears to be an unwise decision, which is actually part of the pattern of your life decisions, practitioners need to have the opportunity to have some sense of knowing that person, in order to make a defensible decision to allow something to continue that might be, in some way, risky or would count as an unwise decision for the person with capacity.

Social workers and other staff are under a lot of pressure to spend small amounts of time with people to make assessments and then set in train self-directed support or packages of support, whatever the arrangement is. There is something about social work distinctively, to my mind, which should be about getting to know people to a sufficient degree—not overly involving yourself but to a sufficient degree—to understand something about their life course: where they have come from, what
their relationships have been like, what has been important to that person about the way that their life has gone, and what meanings they have in various aspects of their life and activities. That should inform decisions that then may need to be taken in their best interests, if they have lost capacity at this point in time. It should inform any matters of restricting choice at this point.

It is really difficult for staff in many agencies now to have that time. I think they try very hard. I would also like to echo something that my colleague here said, about staff working extremely hard in many circumstances to know people and hold on to the values of knowing people in such a way that helps them to make those sensitive decisions. It is certainly not made easy by an “assess-provide, assess-provide” culture. There is work going on in social work at the moment to try to step back from that and reinvigorate the fact that there is an importance and an effectiveness linked to people having the opportunity to develop meaningful relationships with clients for appropriate amounts of time, in order to make exactly those sorts of decisions. There is quite a battle on with that, at the moment.

The Chairman: Could I ask the witnesses to try to be a bit more concise in their answers? It is just the time constraints that we have; I am anxious to get through all of it. I appreciate that it is often important to elaborate on what you are saying. Lord Faulks, can we move on?

Q145 Lord Faulks: It is very much along the lines of the previous questions. I want to ask you about the practical application of the best-interest test and the apparent tension than there may sometimes be between applying the statutory test under section 4 and what you, as a social worker, may think is in the best interests, in the normally understood sense of that expression, of a particular client. It must be, I suppose, for a non-social worker, terribly difficult to stand by and see somebody take a decision that you think is completely wrong but, nevertheless, you are faithfully adhering to the words of the statute. Can you give us some examples of the sorts of situations where this can confront you as a social worker?

Anna Ribas Gonzalez: Firstly, I want to say that there is increasingly good practice in assessing best interest. It is definitely something at the core of social work. A good example would be decisions about accommodation, and it is one of the easiest to understand. When, for example, someone with dementia is living at home and is increasingly at risk, their safety is at risk. That perception of risk usually triggers a capacity assessment. When families or professionals are concerned, that perception of risk—everyone gets in a bit of a standstill and is like, “We need to assess capacity”.

Usually, in some situations, in situations where the person is at home and is at risk, or the person is in hospital, there is an element of urgency, so the decision has to be made quickly. At home, the decision needs to be made quickly because there are probably risks. In hospital, there is the pressure of beds and the person has to be discharged somewhere. Usually the capacity assessment takes place at the same time as the best-interest decision is made. With decisions about accommodation, it is usually a longer process, so social workers are definitely putting a lot of emphasis on taking the time to make those decisions, getting family involved, and carers and other professionals, in making that decision, and of course the person. However,
traditionally, we have put a lot of weight on what we call the duty of care and our responsibility to manage risk. That definitely influences the perception of professionals of what is best for that person.

The final decision, unfortunately, is also influenced by the availability of resources and funding. The person would probably like to move to a home that costs X amount, but the local authority can only fund part of it. I hope that I have more or less responded to the question.

Robert Nisbet: My Lord Chairman, if I could just add one thing, I also feel professionals are not very good at showing their workings-out, as our maths teacher would tell us. They are very good at coming up with the answer, but not showing how they came to that answer. The Mental Capacity Act gives considerable clarity as to the stages you need to go through—the two-stage test of capacity and the five principles. It is very reasonable for anyone to scrutinise a decision, as long as they can show how they have come to that decision. Yes, next month or next year, it might be indicated that it was possibly incorrect but, if they have shown their workings-out at that time, it is reasonable to say that they followed the Act to the best of their ability and what was required.

Baroness McIntosh of Hudnall: I want to say that I am very sympathetic to the view you expressed, Mr Nisbet, that we should be taking a glass-half-full approach to these issues. I am sorry that the question I am about to ask is perhaps a little bit negative. I was struck by what Dr Allen said, at the beginning of the session—I hope I do not misquote—about the lack of transparency and the non-standard nature of assessments. That seems to me to present a risk in itself, but we have received a number of submissions that suggest that either an assumption of capacity or an assumption of non-capacity can be used as a way of getting to a particular end, either to shuffle off responsibility or to take away decision-making powers. It seems to me that that must be connected to the non-standard nature of the way that assessments are carried out and also to the point that you just made, Mr Nisbet, about the general sense that we have that circumstances are often quite unconducive, shall we say, to nuanced decision-making. Would you accept that that is a criticism that is justified, that they are used in this way?

Robert Nisbet: I would. My Lord Chairman, I would say that I have seen records just around tick boxes. They have a standardised form; they tick the box. It does not say, “Show your evidence against the tick”, or we see nothing. Therefore, we cannot really ascertain what informed the decision. What were the drivers of that decision? Yes, it is depressing.

Baroness McIntosh of Hudnall: Therefore, it can obscure what the motivation of a particular professional might have been.

Robert Nisbet: It obscures motivation and it obscures that they have actually considered what is required under the Mental Capacity Act.

Dr Allen: I think often staff do not realise that this is a matter of legally defensible decision-making. To intervene against somebody’s apparent wishes on the basis that...
they do not have capacity is an enormous interference with their rights, particularly for major decisions. There is a lack of standardisation for major significant decisions, and the definition of “significant decisions” needs to be made better. At what point do you really need to be thinking even more comprehensively about showing your workings-out and your legally defensible decision-making, and then how do we monitor that? How do we govern that? How do we manage it? How do we regulate it?

The Chairman: Would it help if there was a standard form that had a box requiring the assessor to put in his or her justification for the conclusion that he or she was reaching?

Robert Nisbet: My Lord Chairman, in some areas they do that, yes. I would also say that is good practice, but it cannot stand in isolation. It has to be validated in terms of discussion, supervision and records accounting for what consultation took place with family members and other people. It needs to be validated, and you could complete your records but you also need to have professional supervision to ensure that you are undertaking your responsibilities, as Dr Allen has said, under the requirements of the law. I pick up that access to good competent supervision—professional supervision—is becoming more and more distant. I do not think it is acceptable, however experienced you are as a social worker, that your day-to-day practice should go without regular supervision, updating and closer scrutiny as to what your responsibilities are and how you are undertaking them.

Q147 Baroness Hollins: I agree with you about the importance of supervision, but I wonder how far good and appropriate decision-making is actually affected by factors outside the Mental Capacity Act. We have heard about the pressure on hospital beds, for example, but the cost of residential care compared to home care, or, for example, junior generic social workers being the ones who are dealing with crisis situations, perhaps without adequate supervision, or just the lack of availability of home carers. I wonder what your thoughts are about that.

Dr Allen: The context of pressure and lack of resources and, in some cases, skill levels as well, and the use of, as you said, relatively recently qualified staff in complex situations are all factors that have to be monitored very carefully. The importance of the ongoing development of, let us say, social workers—although obviously it is all professional staff in this regard—has to be taken seriously. How do we ensure that staff are continuing to develop in their practice and continuing to have supervision? It may be that newly qualified staff get good supervision in the first year and then it might tail off. It is not necessarily just a problem of the newly qualified. It could be the custom and practice that sets in, with people not being refreshed and challenged in their decision-making. In some senses, I see that more frequently.

One of our members wrote an article in Community Care about precisely this. It was called something like “This Care Home or That Care Home”. It is care home or care home in terms of decision-making, and it was resources driving that decision, as well as assumptions around risk driving those sorts of decisions. We still have a way to go attitudinally and in terms of customer practice, but the driver around cost is limiting choices. The MCA, personalisation, safeguarding, guidance and so forth were all conceived at a time when resources were greater. There is a lot less flexibility in

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the system now. What we are looking at in terms of efficiency and effectiveness is not all about money, but there is something about how, for instance, we need to work even more with families, networks of support and whatever residual capacity people have to make decisions and to care for themselves, in the context of efficiency and effectiveness. It is how we match that driver with the quality driver around choice and autonomy. That is a huge struggle for all organisations, which then gets played out at the level of individual decision-making by practitioners.

Q148 Lord Turnberg: My question relates to families and carers who are faced with this bewildering system. They do not quite know what is going on. If the professionals find it difficult, the families find it even more difficult, and it is particularly the case if their concerns are not taken into account. If I can take you back, the reality of the situation out there for patients and carers is that they do not know to whom to go in the first place. They go to the CAB, the local authority’s social care departments, they will go to their GP, or, heaven help them, they will go the accident and emergency department with their demented patient, whose diagnosis is often first made there. In an A&E department, there is really no one who can spare any time for thinking about the Mental Capacity Act and what it might mean. The reality of the situation is that everyone in the NHS and social care is rushed off their feet. Under those circumstances, to get across what is a very complex, difficult and time-consuming effort is not easy. I just wonder how we get through all that. It struck me that what we need is an idiot’s guide or one of these “MCA for dummies” type of publications, for relatives and patients, to know how to get into the system and who to go to. We need some leadership from one organisation, which will take over and take it on, instead of a multiplicity of individuals doing all the bits and pieces in a very amateurish way. What do you think about all that?

Robert Nisbet: My Lord Chairman, I very much agree. Both prior to the Mental Capacity Act becoming operational and post, we have got some excellent publications. They are easy to read. They are quite— I was going to say “accessible” but that is not what has happened. They have somehow reached the shelves of various departments to collect dust. How we can make them more accessible, I am not an expert in that area. How we can market what are very good publications, both in terms of electronic versions, e-learning versions and little TV shows, a bit like a soap opera, which are very good in terms of demonstrating aspects of the Mental Capacity Act; it is all there but, somehow, we have not been able to market it as successfully as, say, a repeat series of Homeland or what-have-you. We are just not grabbing the attention, despite a lot of effort. I do not know why. I really do not know why.

Dr Allen: The voluntary sector, carer organisations and family organisations have a huge role to play in translating some of this into good practice, and already do that. That has to be something that needs to continue. Clearly, the provision of information that is easy to absorb in different formats is important, but often you do need somebody to sit down and talk to you about your situation. That is not necessarily something that the statutory services are always going to be able to do or are best equipped to do it. The carer, service user and voluntary organisations are often very well placed to do that.
There is the role of advocacy as well. Advocacy for families, as well as advocacy for the person being assessed, needs to be considered. Independent mental capacity advocates are very important. There is lots of evidence of very good practice, but they are probably not yet used enough. They are sometimes used quite inflexibly. They will advocate for the individual, but their role with families is often rather unclear. Not specifically in relation to the MCA, but useful for families and individuals who feel lost in the system is the idea of care navigators—people who may be attached to, say, general practice who then help people find their way through the system by showing the map, so that people can go on to find their own way subsequently. We have to think about how we enable people to find their way through.

Lord Turnberg: On that last point about GPs knowing to whom to turn when a patient turns up, or A&E department staff knowing to whom to turn and to have access to someone who can then take it on, that seems to me to be something on which we can build.

Robert Nisbet: If I can just add quickly the point, we have seen a considerable erosion of our voluntary sector and its own capacity. We have also seen those sectors and services brought into the performance-related; they have to deliver on such-and-such a requirement and MCA is not in there. You will not get your money unless you do this, and you ain’t going to get your money because MCA is not part of that. With all due respect to the voluntary sector, there is a great deal of willingness and preparedness, etc, but if they are not going to be funded for that then, in the current climate, they just will not do it.

Anna Ribas Gonzalez: All I wanted to add just quickly is that the importance of all these actions about raising awareness with families, carers and other health professionals needs to be made, but it needs to be made before you get to the point of crisis. That is what you mentioned. Usually the dimension of good capacity and best-interest decisions comes at the point of crisis and, at that point, it is very difficult for families to understand what you are talking about, because their emotions are running high already, and you are adding more stress. It is not a time for them to think, “I think that my mother should be doing this”. You disagree, but it is because of her capacity. I do not think it is fair on them to put added pressure on the complex situation in which they are living. It is very important to start raising awareness before that happens, and most of the time that could happen through health professionals, because they are usually the first point of contact. People will always go to their GPs, to see other doctors and to see other nurses, but sometimes they do not come across social care or mental health professionals until they get to that time of crisis.

Q149 Baroness Andrews: I wanted to pick up on something that, Dr Allen, you said in your evidence, about “longstanding cultural attitudes are proving difficult to shift.” In the course of the evidence, you have identified aspects of that, particularly, despite the Act, the prevailing emphasis on protection, rather than empowerment, which seems to go through the whole of the argument; the difficulty of determining the weight of a significant decision and getting that across to people; the deferential culture, which runs through the whole of the medical profession; and the exclusion of patients from any decision-making process, which is particularly acute in this
situation. These are really fundamental issues, are they not, to the way that we manage the whole of mental health and the health services in general?

You talked about multidisciplinary training. I was not sure how far that was spreading, whether that was local or whether there were national systems for that. It seems to me that trying to attack all those really profound difficulties in multidisciplinary training is a real challenge. Where do you start? Whom do you start with? What is most useful for us to think about in that sense, which would be manageable for you?

Baroness Barker: Could I just add, while you are thinking about your answer, when you spoke about this before, you specifically mentioned doctors? You did not talk about other staff; you specifically mentioned doctors.

Dr Allen: As I said, I work in an NHS context, so I have personal experience, day-to-day. It is about healthcare more broadly than that. The deferential part relates to doctors’ decision-making, more than nurses’ decision-making or psychologists’ decision-making. There is that kind of hierarchy. The different professions in health are different in many ways, characteristically in their attitude towards enablement as well. OT is often all about enablement, so I think there are differences there for instance. But the overall healthcare system is diagnosis-intervention: a “This is good for you” approach. That is actually a driving dominant way of operating, particularly at points of crisis, at points of urgency and at times of pressure.

In terms of where we start with shifting culture and the role of training, we have a national programme around best-interest assessors under Deprivation of Liberty Safeguards. That has been patchy in its quality. There has been some real consideration of how good those programmes have been to train people for that particular role in relation to DoLS. We may want to be looking at mandating the development of national programmes of training that are in some way accredited for, maybe, leaders around the MCA. Out of that, there would then be the high benchmark. Out of that, we would clearly clarify the capabilities for all staff, at different levels of responsibility, different levels of frequency of use and so on. We have the DoLS framework upon which we might build, but it definitely needs to be revised for the overall implementation of the MCA, not just the DoLS aspect, and systems leadership, so locally. It has happened in safeguarding. There is a lot of useful sector-led, (as in social-care-sector-led) guidance and there are some competency standards, which are widely used now in relation to adult safeguarding.

Could we not have something much clearer around the MCA, and identify who you need in your local system to be really trained and have that leadership role, what the other levels of training are that you would want to see, and how you are being held to account? I do not think that would answer all of the cultural issues. The leadership part in that is important, in terms of shifting culture, and that is not just about training; it is also about senior leaders taking that on.

Can I also add that I think it is a top-down/bottom-up matter? One of the reasons why, in some ways, we are in a position where this feels like a rather messy implementation, is of course that the people affected are some of the least empowered in society. As I said earlier, advocacy is only sometimes available for

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those people. How do we ensure that the voices of user groups, carer organisations and family organisations are consistently heard about local experiences falling short? Who hears that and who acts on that?

Q150 Lord Patel of Bradford: Taking your point up about the basic shift in culture—I trained as a social worker, and this was part of my DNA—how far are both of your organisations happy with what is being provided at qualification stage to students? You have talked about hands-on experience. Placements, I assume, still carry on. Where is this built in? Is there sufficient evidence there?

Robert Nisbet: My Lord Chairman, I have concerns around the level of quality of teaching in relation to the law and the law that is required for social workers to understand and implement. I say that based on some recent research evidence undertaken by some esteemed colleagues in various universities, who undertook a piece of research observing social workers in adult care, and how they used or applied the law. It was very weak. We have that as an issue within colleges, but also in terms of when you go into social work. I have to say I am concerned about how social workers are updated in their training qualifications. Fine, if you want to become an AMHP but, in relation to access to other training, given the tightness of budgets and the cover arrangements, everything almost pressurises so that no protected time is provided—there are exceptions—and so training is not valued.

Why do social workers think they should take responsibility? They should do, but often they do not, because they often do not feel that their updating in practice and their professional development is being valued by their employer. They say, “Why should I bother?” which is a shame. It is learned helplessness, in a way. We get into this track where training is not adequate. Even when it is provided, getting people to be able to attend is often very difficult. I know that from my own experience.

Also, I think the thresholds for what is required as evidence for continued professional development are way too low. I do not understand that if you just say, “I had a conversation with my supervisor”, you should be able to say, “That counts towards my continuing professional development”, or “I read this article in Social Work Today or Community Care; therefore, it counts.” I do not understand that. I would have to say that is unacceptable. Yes, you should read the article, but there is a lot more to it, in terms of how you apply it.

Dr Allen: I would just like to add that, through social work reform and the work of the College, there is now the Professional Capabilities Framework. It is the new framework for social work development, from qualifying through to the most advanced level. It is very clear that that is about developing social workers throughout their career. If you are a social work manager or a principal social worker leading across a council, you will attend to your development across a range of domains, which are about skill, knowledge and also about rights. That framework is, for the first time, in a sense, a comprehensive capability holistic framework. I think it does provide the right framework upon which we need to now build post-qualifying frameworks, CPD frameworks, which have come and gone, and they have been patchy.
Some local authorities and other employers do a very good job in terms of providing a range of rounded development opportunities. That is being affected by the cuts—we know that—and it is also something that is patchy. It is not all doom and gloom, in relation to this sort of development. I chair the mental health faculty at the College. The Approved Mental Health Professional role is the most standardised, comprehensive post-qualifying framework that we have in social work, obviously coming out of the old ASW role. We do not have equivalents of that in adult social work. The new chief social worker is interested in having that. It is within those frameworks that we could see a real shift in solid career-long development in exactly a matter like this.

Q151 Baroness Barker: I want to wind up with a couple of questions about access to justice. I will preface these questions by saying that, Dr Allen, I think you are the first witness to talk to us about the fact that the law was designed or drawn up at times when there were more resources. I am also very mindful of your opening statement about the fact that there are a number of bodies that are responsible for implementing this law, but no one body that has overall responsibility for gathering the data. Those two are germane.

In the context of those two things, BASW, you have advocated that there should be much greater use of mediation services in order to avoid people having to go to the Court of Protection, which is seen to be costly, cumbersome and difficult. Would you like to tell us a bit more about how you would see that operating, particularly in relation to the other organisations?

Robert Nisbet: My Lord Chairman, we know that the Court of Protection is overwhelmed and we also know that many cases come to the Court of Protection that would have benefited from earlier intervention and earlier mediation between different parties and views. Mediation is not a cheap alternative. It has to be done correctly, professionally and competently, and it also requires a degree of independence. What we have lost is that agencies have understandably, because they are trying to meet ongoing costs, been proactive in putting money aside to develop those services to be proactive. It has been very difficult for them.

The consequences are that, without mediation services, without competent good training and access to training, they can end up in situations where they find themselves in the Court of Protection. We know of one particular case that had a very high profile. They end up spending an awful lot of money on legal fees. There was one authority that was actually fined by the Court of Protection, which was unheard of, as I understand it. There is a very strong argument for saying what mediation can achieve.

The other thing is that, as I mentioned before, with the breakdown in confidence about public sector services, mediation, because of its independence, may be seen to be more accessible and fairer to families and members. Also, having seen mediation work, it is a very skilled responsibility, and, when it is done well, it does achieve very good results and outcomes for both parties. It is very important. We see it in other areas. Mediation is very strongly supported within family courts, particularly around relationship difficulties, divorce, etc. Mediation is your first port of call rather than going to court, and I cannot see why that should not be the case with the MCA. In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
other thing is that people have tended to see the IMCA service as mediation; they are not there for mediation, so we need to be clear about that.

**Q152 Baroness Barker:** You also talked about increased regulatory powers for CQC, and Dr Allen has talked about the influence of CQC on developing the culture of organisations. Can you just tell us what further resourcing and structures you think CQC would need to have in order to bring that to fruition?

**Robert Nisbet:** My Lord Chairman, firstly, I do feel that now CQC has picked up on the MCA and DoLS, it has made a significant difference. We have seen services starting to be proactive in ensuring that their house is more in order on MCA. There is still a long way to go. I also feel there would be a benefit of CQC having a similar body to the Mental Health Act Commission, which is now part of CQC, particularly in inspecting the supervisory bodies to see how supervisory bodies are undertaking their responsibilities in how they undertake authorisations, whether they have enough BIAs available, the training of BIAs, etc, and also in terms of scrutinising far more closely the authorisations for Deprivation of Liberty. I do not feel competent enough to talk about the other powers and responsibilities that the previous Mental Health Act Commission has had, which is now under the CQC, but I do feel that they are yet another very important part of scrutiny and of bringing the level of services up to the mark that they should be.

**Dr Allen:** I believe the CQC is looking to integrate the Mental Health Act Commission function into their compliance functions more, in their scrutiny of mental health organisations. They are also now scrutinising in the community. They go into regulation in the community, as well as in patient services, in for instance mental health trusts. Within that, what I think we need to know is that they are grappling very strongly with the implementation of MCA as well as the Mental Health Act. The relationship between the Mental Health Act and the MCA is something that they can help to regulate and enforce in a meaningful way.

There is something about the way the CQC works with providers to ensure that the expectations are absolutely clear and that there is shared understanding across the sector about what is required. The current development of the CQC is moving much more in that direction, which will be absolutely essential in this area, because there is quite a lot of confusion, at many levels, in the relationship between, for instance, the Mental Health Act and the Mental Capacity Act. The two bits of legislation do not easily fit together. They come out of different legal and philosophical routes, in some ways, and have very different histories. It will be very important that the CQC can help to make sure that providers are really clear about what is expected in order to show good practice and compliance.

**The Chairman:** Thank you very much for your evidence. We are very grateful for it. It has been extremely useful for us, and it has supplemented your written submissions, which were also very detailed. Thank you very much.
SUMMARY OF RECOMMENDATIONS

• The MCA Committee should recommend an urgent review of the implementation of the Deprivation of Liberty Safeguards (DOLS): the inappropriate use of DOLS poses significant risks to the rights of people in vulnerable situations. The MCA Committee should support the calls of the Health Select Committee and others for an urgent review into the implementation of DOLS.

• The safeguards in the MCA should be improved, and access to these safeguards should be increased: additional steps are needed to ensure people who are affected by the MCA have access to these important protections, and improvements to the safeguards are needed to ensure they protect people’s rights.

• Making human rights explicit in the implementation of the MCA: adopting a human rights approach to the implementation of the MCA would help ensure that people’s human rights are being considered when the Act is applied in practice. This would include promoting the five core principles of the MCA across health and social care structures and beyond, which are based on key human rights principles. If they were “common knowledge” across the NHS and in social care settings, this would go a long way towards ensuring the MCA is correctly implemented and applied in frontline practice.

• Investing in implementing the MCA: there is a lack of accessible information and training available on the MCA for practitioners, advocates, individuals and their carers and families. Increased investment at all these levels is needed to ensure the MCA is correctly understood and applied. Further research is needed to bring together and build on recent studies to help create a more informed picture of the challenges faced in implementing the MCA, and help inform the solutions.

• Accessible Code of Practice to support the implementation of the MCA: The MCA Code of Practice could be re-drafted to make it more accessible, as well as drafting tailored codes of practice for particular audiences to make it relevant and accessible for practitioners in different fields.

• Monitoring and Regulation of the MCA by the Care Quality Commission: The CQC should monitor the use of the MCA (including the power to investigate service user complaints and a duty to visit hospitals and care homes) as an important step towards ensuring the MCA is correctly implemented and applied in practice.

• Increasing Commissioners awareness and understanding of the MCA: Commissioners should be provided with training and resources on the MCA, and accountability measures should be introduced to ensure Commissioners recognise their important role in ensuring people who lack capacity have their rights protected.

• The MCA Committee should request that the Joint Committee on Human Rights reviews the implementation of its report one year after publication: the JCHR is ideally placed to continue the work of the Committee once it ceases to function.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
INTRODUCTION

1. The British Institute of Human Rights (BIHR) welcomes the establishment of the MCA Committee, in light of serious human rights issues which have been exposed in recent times. In particular we are pleased to see the scope of the inquiry includes the framework of the Mental Capacity Act (MCA) and how it works in practice, and the use of Deprivation of Liberty Safeguards (DOLS).

2. Issues about mental capacity are not remote; they can touch any one of us at various points in life, for example when people develop dementia, when illness or injury leads to incapacity, or when people have learning disabilities. When we experience moments of vulnerability, human rights provides a vital safety net for us all. There are concerns that people subject to the MCA are falling through the gaps, and thus it is vital to assess whether the MCA and the implementation of the MCA are meeting the basic minimum standards set out in the Human Rights Act (HRA).

3. The cruelty of cases such as Winterbourne View and reports by Mencap and the Care Quality Commission (CQC) have highlighted the indifference and abuse that people with capacity issues can be subjected to within health and social care settings. They are sobering reminders of how, when we are placed in situations where others have power over us there is potential for that power to be abused or misused which engage our most basic human rights. This includes risks to, and at worst violations of, fundamental rights protected by the HRA including the right to life (Article 2), the prohibition on inhuman and degrading treatment (Article 3), liberty (Article 5), fair trial (Article 6) and respect for private and family life (Article 8) and non-discrimination (Article 14) on the basis of a person’s capacity or mental health.

4. Section 6 of the HRA places legal duties on public authorities - including healthcare services, local authorities and social services - to respect, protect and fulfil people’s human rights in their day-to-day practice. This includes in the way they make decisions and exercise their powers and functions under different laws, such as the MCA. In some cases the HRA may also require positive action to protect rights. This can include protecting a person when they are known to be at risk of having certain rights abused (e.g. Articles 2, 3 and 8) and having the right procedures and systems in place to protect our rights. The HRA is therefore an important tool for assessing how well the MCA is doing at protecting people’s rights.

5. Undertaking post-legislative scrutiny enables law-makers to review whether the law is fit for purpose, including identifying gaps, issues with the framework and with implementation, as well as good practice. However, we also note that procedurally the Select Committee will cease to exist once it reports, which may compromise the extent to which the Committee’s recommendations are followed up and implemented.

6. We therefore suggest that the MCA Committee should request that the Joint Committee on Human Rights reviews the implementation of its report one year after publication. Given that the MCA Committee was formed in response to concerns that practices under the MCA may not be respecting human rights, the JCHR would be ideally placed to perform the review task. In addition, it is vital that in order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
the MCA Committee recommendations feed into relevant current and planned initiatives such as reviews around Winterbourne View, the review of the Mental Health Act Code of Practice and standards on restraint, and the conclusions of the Post Legislative Committee on the Mental Health Act 2007.

7. BIHR works to bring rights to life, taking the law beyond the statute books and courtrooms and into everyday practice. Since the passing of the HRA we have undertaken a range of partnership work within the health and social care field developing human rights approaches to the development and delivery of policy and services. We have, in recent years, developed particular experience of practice-based human rights work in mental health settings, including work with statutory service providers and voluntary sector advocates. Our work reveals the following:

• There is a lack of awareness about the how the Human Rights Act relates to practice, including the implementation of the MCA and how the actions of professionals can pose both risks to people’s rights as well as opportunities to respect, protect and fulfil rights.
• Whilst there are pockets of good practice and expertise, there is a general lack of awareness about the MCA and how to implement it.
• There is a lack of information about rights, and the safeguards that exist to protect individuals’ rights under the MCA (for example information about advocacy or the Court of Protection) available to individuals affected by the MCA, their families and carers.
• More could be done to ensure that independent advocates have greater capacity and confidence to recognise and raise human rights issues.
• Across the board – amongst service providers, advocacy services and at an individual level – there is a lack of access to resources and on-going training on the MCA and how it interacts with other mental health law and human rights.

8. We therefore recommend investment in on-going training for frontline professionals, and the development of accessible information and resources for people directly affected by the MCA, and their advocates, carers and families. These resources and on-going training should include explicit references to human rights and how the MCA interacts with the HRA.

9. Importantly, our work also shows that adopting a human rights approach can help change organisational culture and practices, which focus on the individual person, empowering staff and patients. This can has been especially the case in mental health and learning disability services. For example our work with advocacy organisations shows how building the capacity of advocates to understand the interaction of the HRA and MCA and to deploy human rights arguments when people with capacity issues are being treated unfairly or poorly helps to change behaviour and practice and achieve better outcomes for those people.

10. Our work with the public sector also shows how building human rights capacity of staff can help practitioners to develop respectful and dignified services which ensure people with capacity issues are able to exercise as much control and choice as possible. A human rights approach also assists practitioners to make difficult decisions, providing a framework to identify and balance relevant
considerations. This includes ensuring proportionate positive action is taken to protect and safeguard people, when necessary.

Example from BIHR’s practice work:

The Mersey Care Learning Disability Service has developed a human rights approach to risk assessment and management, following involvement in the Department of Health Human Rights in Healthcare project, with capacity-building and support provided by BIHR. In the first phase of the project we developed a number of practical resources to support this work including the ‘Keeping Me Safe and Well’ risk assessment manual. This was designed in collaboration with service users using stories and pictures to explain situations and a simple traffic light system for risks, to ensure risk assessment was “done with” rather than “done to” people in contact with the service. The tool ensures that any risks that are identified are discussed with service users, and that any restrictions on a person’s rights as a result of these risks are lawful, legitimate and proportionate. Interestingly, staff now often refer to ‘rights maximisation’ rather than ‘risk containment’.

OVERVIEW AND CONTEXT

11. The MCA has strong roots in human rights. A number of high profile human rights challenges to mental health law identified a lack of protection of the rights of people who lack capacity. In response to these challenges and campaigning by disability organisations and others, the Government recognised the need for further legal protection in this area and drafted the MCA. The MCA was designed to protect individuals who cannot make decisions for themselves. In practice the MCA has the potential to either maximise rights or pose potential risks to people’s human rights, and ensuring the MCA is correctly implemented and applied is vital for ensuring individual human rights are safeguarded.

12. In many ways the MCA is a progressive piece of law which has the potential to strengthen our rights protections. In particular the five guiding principles of the MCA are about ensuring capacity decisions are made in a way that respects, protects and fulfils people’s human rights.

The MCA guiding principles:

Presumption of capacity: this recognises that everyone has the right to make their own decisions if they have the capacity to do so.

Maximising decision making capacity: people should be supported and empowered to be able to make their own decisions.

Right to make unwise decisions: people have the right to make decisions that others might think are unwise.

Best interests: any decision or action carried out on someone’s behalf must be in their best interests.
Least restrictive option: any decision or action carried out on someone’s behalf must be the least restrictive on a person’s rights or freedoms.

IMPLEMENTATION AND DECISION-MAKING

13. We know from our work with practitioners in the field of health and social care that much of the evidence of how the MCA is being applied in practice is anecdotal. For example, in 2013 BIHR delivered three open courses on Mental Health and Human Rights to 200 mental health professionals across England as part of our Human Rights in Healthcare Project. At every event practitioners voiced concerns that the implementation of the MCA is in some instances risking vulnerable people’s basic human rights. We encounter this anecdotal evidence about the MCA on a regular basis. Whilst some research exists we believe further research is needed to bring together and build on recent studies to help create a more informed picture of the challenges faced in implementing the MCA, and help inform the solutions for addressing these problems.

14. In practice, we believe there is limited understanding of the relationship between the MCA and human rights. The HRA should be the lens through which other laws and policies are applied. This means for example, that when determining what constitutes a person’s “best interests” reference should be made to human rights. This will enable decision-makers to ensure they are placing the individual at the centre of the process, that there is consideration of their rights and there is a framework for balancing these rights against other appropriate considerations such as safety and the rights of others. In this way using the HRA in frontline practice is not only about ensuring respect for fundamental rights, it is also a practical decision-making framework for professionals, based on universal legal standards, rather than individual ethics. However, the extent to which this is happening on the ground remains of concern.

15. We refer the Committee to Evidence submitted by Pembrokeshire People First (PPF) – a user-lead service for people with learning disabilities. PPF used BIHR’s “unofficial guide” to the Committee Call for Evidence to work with a groups of service-users to ensure their voices are heard within the Committee’s assessment. PPF’s evidence suggests:

“Overall, the advocate experience and the general consultation response here reflects that of Williams et al that the principles of the MCA contrast with actual practice and that the attitude of those in positions of power and control are often a barrier to independent decision-taking and choice-making by people with learning disabilities.”

16. We suggest that the MCA Committee recommends making human rights explicit in the implementation of the MCA. The HRA underpins the MCA, however to ensure human rights are being respected and protected when applying the MCA, the Human Rights Act must be explicit in the implementation of the MCA. Adopting a human rights approach to the implementation of the MCA (for example in designing policies on the MCA, delivering training, and drafting information on the MCA for practitioners, service-users and their families/carers) would help ensure

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that people’s human rights are being considered when the MCA is being applied in practice.

17. We also suggest that the MCA Committee recommend promoting the five core principles of the MCA across health and social care structures and beyond. The five core principles of the MCA are key to understanding how to apply the MCA in practice. Our work shows if these basic principles, which are based on key human rights principles, were ‘common knowledge’ across the NHS, in social care settings, and other relevant systems and structures this would go a long way towards ensuring the MCA is correctly implemented and applied in frontline practice.

18. Much of our work at BIHR involves making human rights law accessible and relevant to frontline practitioners by delivering high quality training and designing and developing accessible practical tools and resources. We know from our work in this area that practitioners need the right resources and training in order to apply the law in practice. Frontline practitioners cannot be expected to be legal experts on the MCA and they must be supported with the right resources to ensure they understand the MCA and how it should be applied in practice.

19. We therefore suggest the MCA Committee considers recommending the MCA Code of Practice be re-drafted to make it more accessible, as well as drafting tailored codes of practice for particular audiences (e.g. similar to the various Codes of Practice that accompany the Equality Act 2010) to make it relevant and accessible for practitioners in different fields. In addition, the Code of Practice must be made accessible for people directly affected by the MCA, to bring it in line with human rights principles, including the UK’s commitments under the UN Convention of the Rights of Persons with Disabilities.

20. The MCA provides a number of important safeguards to ensure decisions that are made on behalf of a person who lacks capacity, or decisions that are made about a person’s capacity, are made in a safe and correct way, which respects basic human rights. Our work with advocacy groups consistently reveals serious concerns that these safeguards are not working in practice, particularly around lack of knowledge of and referrals to Independent Mental Capacity Advocates. This is borne out by research, for example:

“The statistics show that referrals to Independent Mental Capacity Advocates (IMCA) have been lower than expected, and the number of complaints and litigation resulting from IMCA referrals is concerningly low, suggesting they are only infrequently challenging decision makers or assisting P to do so.”

21. Our experience of working with individuals, advocacy and public sector services suggests that access to an advocate in general and to IMCA’s is very important in ensuring respect for the basic rights of people with capacity issues. PPF’s evidence shows how important it is for people with learning disabilities to have access to an advocate to help them feel empowered, to being able to raise their voice, be heard and be included in decisions which affect them:

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• “I think people make snap decisions without seeing me day to day, what I’m like when I get out of bed in the morning or when I go to bed at the end of the day.”
• “Social people are a waste of space. It was not until I had Sheila and PPF (advocates) that they did start listening to me. They listened to me after.”
• “We are just products to them (social workers), not people. You could probably go so far as to say that we are just cattle being herded.”
• “Even when I’ve had a problem I’ve had to sort it out myself. Apart from PPF (advocates) I’ve never had any help off anyone else.”
• “Most of the time I don’t have anybody. I just do it by myself… My husband always helped me when he was alive. Now I just have to cope on my own unless I have Sheila (advocate) or someone like that that.”

22. PPF’s evidence also provides useful examples of how people with capacity issues may be deprived of their rights under the guise of “best interests” and the importance of advocates in helping to challenge such poor practice:

“An example of that is of an advocacy-partner who was the sole beneficiary of his family estate. His capacity to handle his finances was doubted and social services regularly discussed his ‘best interests’. It was only after his advocate pressed the issue that a formal capacity assessment was done – by a doctor chosen by a solicitor referred to by the local authority. The assessment result was that there was a lack of capacity. This caused great distress to the advocacy-partner who decided to challenge the assessment. Eventually the original assessment was overturned and it was agreed that, indeed, the advocacy-partner was able, with some support, to manage his own finances. It should be said that the original assessor did not have adequate knowledge about the person and the advocacy-partner was so extremely anxious about meeting a doctor and about the whole process that he was unable to fully express himself. It took advocacy support for rights to be explained, for people and processes to be challenged and for the eventual agreement that this person did – as he claimed all along – have the capacity to make his own decisions. The MCA system worked in this case but only because there was an independent advocate to explain rights and support the challenge: the availability of independent advocacy may be key to the successful implementation of the Act and holding ‘professionals’ to the spirit of the Act.”

23. We have also been informed of practices within health settings where capacity assessments are not being undertaken in relation to physical health decisions. A number of examples have been shared with us involving people with dementia (or similar conditions) who have been given medical treatment under the use of “best interests” without undertaking a capacity assessment. In one example an older woman was given treatment following a fall with no consideration of her capacity to be involved in the decision-making process. When the consultant in question became aware of this they raised concerns that such an approach was in fact not in the patients “best interests” if it did not consider her capacity and her human rights.

24. Similarly, presumptions around what is in “best interests” and lack of capacity, manifests itself in the right of people with learning disabilities to engage in
relationships (as protected under Article 8). PPF’s evidence flags the following example:

“An example of that is of a young female advocacy-partner who suddenly had to have staff present when she was meeting her boyfriend. She did not know why this was; staff told her it had to happen. It turned out that staff had presumed that she lacked the capacity to decide whether to or how to progress the relationship. No assessment had been carried out. No support had been given to help the decision making.”

25. We also note that concerns have been raised with us around the costs of making an application to the Court of Protection (coupled with the reductions in legal aid). Our experience paints a picture of safeguards which are not working consistently in practice and additional steps are needed to ensure people who are affected by the MCA have access to these important protections. We believe the Government must raise awareness of the IMCA service (and when to make a referral) amongst professionals across the field of health and social care, and make the Court of Protection more accessible by providing better information about the Court, reducing court fees, and increasing access to legal aid.

26. We therefore suggest that the Committee recommends improvements in, and access to, safeguards under the MCA. Improvements could include:

- Increasing the accessibility of the Court of Protection, such as ensuring access to legal aid, reducing the cost, and introducing measures to ensure the meaningful participation of the person affected;
- More accessible information to be made available about Independent Mental Capacity Advocacy (IMCA) services and to encourage the use of IMCAs;
- Automatic referrals to IMCA services where safeguarding issues have been raised.

27. Commissioners of health and social care services are integral to ensuring the MCA is correctly implemented and applied in practice. This means Commissioners should be properly trained and equipped to ensure their commissioning decisions and practices support people who lack capacity to be engaged and involved in decision making. This also means Commissioners should be accountable for their commissioning decisions and practices, particularly in relation to commissioning local advocacy services and ensuring individuals and their families have access to accurate information about their rights and what the MCA means for them.

28. We therefore recommend Commissioners should be provided with training and resources on the MCA and human rights. Accountability measures should be introduced to ensure Commissioners recognise the important role they have in ensuring people who lack capacity have their rights protected.

29. We note that the Care Quality Commission (CQC) already monitors and reviews the use of the Deprivation of Liberty Safeguards (part of the MCA) and the Mental Health Act (MHA). We know from our work with NHS service providers and organisations providing advocacy services in the field of mental health that monitoring of the implementation of the MHA by the CQC plays an important role in order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
(alongside other measures) in helping drive up standards of care. We therefore recommend a parity of review functions and that the CQC monitors the use of the MCA (including the power to investigate service user complaints and a duty to visit hospitals and care homes). This would be an important step towards ensuring the MCA is correctly implemented and applied in practice.

DEPRIVATION OF LIBERTY SAFEGUARDS

30. The Deprivation of Liberty Safeguards (DoLS) are part of the MCA. They are intended to offer additional safeguards for people who lack capacity to ensure they do not have their freedom restricted more than is absolutely necessary, and that any restriction is in their best interests. The DoLS were created as a result of a legal case using human rights to challenge mental health law. An autistic man had been deprived of his liberty whilst receiving treatment at Bournewood Hospital, however he was not formally detained (“sectioned”). There were no specific guidelines or safeguards for adults without capacity who are deprived of their liberty in hospitals and care homes whilst voluntary patients. The Court found that the detention of the man had been unlawful, and identified a gap in mental health law. The DoLS were designed to plug this gap by requiring an authority that wishes to deprive an adult who lacks capacity of their liberty to do so in a way that respects their human rights. In practice this is the purpose for which DoLS should be used.

31. However, evidence – both BIHR’s experience and from wider sources and research – suggests that the DoLS may not be being applied in way which comply with human rights. The case of Mark and Stephen Neary is a very stark reminder of how the system can breach the human rights of people with capacity issues and the impact this can have on family members. In this case the judge said:

"[Para 33] The DoL scheme is an important safeguard against arbitrary detention. Where stringent conditions are met, it allows a managing authority to deprive a person of liberty at a particular place. It is not to be used by a local authority as a means of getting its own way on the question of whether it is in the person’s best interests to be in the place at all. Using the DoL regime in that way turns the spirit of the Mental Capacity Act 2005 on its head, with a code designed to protect the liberty of vulnerable people being used instead as an instrument of confinement. In this case, far from being a safeguard, the way in which the DoL process was used masked the real deprivation of liberty, which was the refusal to allow Steven to go home.

Poor decision-making processes often lead to bad decisions. Where a local authority wears a number of hats, it should be clear about who is responsible for its direction. Here, one sub-department of Hillingdon’s adult social services provides social work support and another is responsible for running facilities such as the support unit. At the same time, senior social workers represent the supervisory body that determines whether or not a DoL authorisation should be granted…The tail of service provision, however expert and specialised, should not wag the dog of welfare planning. Unfortunately, this case was characterised either by an absence of decision-making or by a disorganised situation where nobody was truly in charge and it was consequently possible for nobody to take responsibility. At various stages during the hearing, I asked Hillingdon witnesses to explain who was answerable for various
actions, but no-one could say. Even when its position came under strong and public challenge towards the end of the year, and when at least one very senior social work manager had serious concerns about what was happening, this had no effect on the corporate position.

…Where, as here, a supervisory body grants authorisations on the basis of perfunctory scrutiny of superficial best interests assessments, it cannot expect the authorisations to be legally valid.”

[para 202] ...there is an obligation on the State to ensure that a person deprived of liberty is not only entitled but enabled to have the lawfulness of his detention reviewed speedily by a court. The nature of the obligation will depend upon the circumstances, which may not readily be transferable from one context to another. In the present case, I have already found that the three matters together – no IMCA, no effective review, and no timely issue of proceedings –made it more likely than not that Steven would have returned home very much earlier than he did. Those omissions had consequences, and Hillingdon thereby defaulted on its obligations towards Steven. I accordingly find that they amounted to a breach of his rights under Article 5(4).”

32. We also note in this regard:
   • Winterbourne View Hospital Report, which notes DoLS-related issues at various points including “individual patient records gave rise to concerns in that they did not accurately convey patients’ mental health status and whether Deprivation of Liberty Safeguards were considered.” (para 2.9)
   • Research by Lucy Series collating various Government statistics: “Use of the deprivation of liberty safeguards has been underwhelming and extremely variable – it appears there is a postcode lottery in the Article 5 protections offered by the safeguards, both in terms of when they are applied, and how effectively people’s rights to advocacy and challenge are upheld.”
   • CQC Report on the Operation of the Deprivation of Liberty Safeguards in England (2011/12) which revealed low rates of applications to local authorities and a real lack of awareness of the MCA and DoLS amongst health and social care professionals.

33. The inappropriate and inadequate use of DOLS poses significant risks to the rights of people in vulnerable situations across the country, including to not be arbitrarily deprived of liberty (Article 5) without legal authorisation or access to safeguards. There may also be other risks to individual rights in relation to issues such as restrictions on family visits and maintaining relationships, protected by Article 8 of the HRA.

34. BIHR’s work with advocates and service providers shows how raising human rights capacity of frontline staff in both sectors can help develop practice in which DoLS are used for their intended purpose: to protect the rights of people in vulnerable situations.

35. We note that the Health Select Committee recently published its post-legislative scrutiny report on the Mental Health Act 2007, including the DOLS, on which it said:

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“The committee found that application of the safeguards is variable and on many occasions those responsible for ensuring patients are protected by them have failed to do so. There is considerable confusion around the scope of the safeguards and how and when to apply them in practice. The evidence the Committee heard regarding the application of DoLS revealed a profoundly depressing and complacent approach to the matter. There is extreme variation in their use and we are concerned that some of the most vulnerable members of society may be exposed to abuse because the legislation has failed to implement controls to properly protect them.”

36. We therefore suggest the MCA Committee recommends an urgent review of the implementation of the Deprivation of Liberty Safeguards. The Health Select Committee report recommends:

“There is extreme variation in their (DOLS) use and we are concerned that some of the most vulnerable members of society may be exposed to abuse because the legislation has failed to implement controls to properly protect them. An urgent review of the implementation of DOLS should be undertaken by the Department of Health and presented to Parliament, together with an action plan for improvement, within 12 months.”

The MCA Committee should support this recommendation and reiterate the need to conduct an urgent and thorough review of DOLS.

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that had three versions at different times, there were lasting powers of attorney and so on. From a narrow perspective, we were effective and we achieved those targets.

Then in 2009 the deprivation of liberty safeguards were introduced, which was the second phase of implementation. The period 2007 to 2009, from the Department of Health’s perspective, was certainly a much tougher timescale. That was much more process driven. It required us to engage with universities to train people against a very unusual timescale. From that perspective, we can say we did achieve the targets and timescales to bring the legislation, the organisations and processes into place.

We can say that there is a legacy: the local implementation networks by and large carry on, the regional networks carry on, and there is an online knowledge community that has more than 4,000 members and which we set up as a parting gift. If we are judged against that standard, we were effective. That is not the same as saying the Act is fully implemented or understood. That is a different test. That would be my comment in relation to that.

Q186 The Chairman: Can you tell us why the programme was stopped in 2011, and do you know what programmes or resources are still produced on a national scale?

Paul Gantley: The original implementation programme was cross-government. The lead department at the outset was the Department for Constitutional Affairs and is now the Ministry of Justice. It is interesting to note that despite some comments in Parliament at times that this is one of the most significant pieces of health and social care legislation of recent years, it was not led as a piece of health and social care legislation. It was led by the Department for Constitutional Affairs and by the Ministry of Justice, which is an interesting thing to note.

When it came to 2007, and the Office of the Public Guardian and the Court of Protection were in their new form, the Department for Constitutional Affairs considered its implementation done. Its business was getting those new processes into place. The Department of Health continued in the first instance because we were looking to continue to embed, for example, the IMCA service, which was still relatively new. Then of course we had a quite different beast to contend with in terms of implementation, which was the deprivation of liberty safeguards. The continuation at that point was not so much about implementing the Mental Capacity Act; it was about implementing the deprivation of liberty safeguards. It was a different direction.

When it came to 2011, when we did depart, I think that was part of a wider decision around the Department of Health austerity cuts and so forth. I do not think there was necessarily a particular decision that said our time was done. It was very much that people doing a similar task were going across the board. I might not argue this, but you could argue that six years was a good run for a central government implementation programme. I suppose that knowing whether something has been achieved depends on what you were seeking to achieve at the outset. I am not sure we necessarily had that. I was asked very early on, possibly at the first meeting I went to of the cross-implementation programme, when I would know that I had succeeded in training everybody on the Mental Capacity Act. I said, “You could have

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my resignation whenever you want it”. How do you know that you have trained three million workers? How do you know you have communicated with three million carers? How do you know you have got something through as a message to two million people lacking capacity? How do you know? I think it is difficult to answer that question.

The end came because of a wider political moment. That has left behind a legacy. We have the local implementation networks, the regional networks and the online community that continue. There is some success there; there is ongoing funding that is maintaining the profile locally and regionally. What is lost at the centre, though, is a central focus. For example, we finished in roughly March 2011, and in February 2011 we issued some guidance around the case law as it was at the time, but there has been no more guidance from central government about case law. The resources that come from the centre now are much more around reporting and auditing. There are annual reports from the Health and Social Care Information Centre around deprivation of liberty safeguards; there is an annual report from the Department of Health around IMCA activity; the Department of Health has had some commissioned research come through, some of which I am sure has been shared with you. The central emphasis now, though, is more about activity and numbers. One of the things the field has commented on missing is something that is more analytical or something that is more about guidance—for example, with case law development. That would be perceived to be a gap that others have reported to me in the last two and a half years.

Patricia Kearney: Shall I say something from the Social Care Institute for Excellence? Our remit is to gather and analyse knowledge about what works and disseminate that into practical resources. This is an interesting topic from our point of view, because it is fair to say that I do not think there is a rigorous evidence base yet for the impact of this work. I would also say that I think it is fair not to expect it in the case of emerging practice like this. The legislation is on the whole well drafted, and its principles and definitions well regarded in this sector, but that is only the start of it. It is a hearts and minds job around cultural change. Culture is ‘how we do things around here’ here, so we are talking about major professional behaviour change as well as public awareness and perception. Those are ongoing activities.

There are several challenges. There is a huge and diverse constituency of professional audiences before you even get to think about carers and people who use services, so that kind of shift takes time. The Act has supported and informed a growing understanding running alongside the Act’s implementation around personalisation and person-centred care, and dignity. Our dignity guide is our most visited resource and our Dignity work explains how this should be understood as closely linked to the MCA. The landscape has changed too: the recent focus on MCA and DoLS monitoring that CQC has announced in its strategy, the Care Bill’s aspirations around individual care and control, and the establishment of adult safeguarding boards. These are all movements that I think enforce and take forward the spirit of the MCA. It is about seeing it as a staged process. We have the frameworks in place: the what to do and why to do it. We are still moving on the how to do it and what the impact is if you do it right.
Sanchita Hosali: I would probably echo a lot of what has already been said. From the British Institute of Human Rights’ perspective, we do a lot of practice-based work with both service providers, and advocacy groups and individuals accessing services. We have a perspective that works with both sides of the coin. From our practice-based work, the message we get time and time again from all the audiences is a real lack of understanding about the MCA and what it really means in practice. Quite astonishingly for us, there seems to be the almost complete invisibility of the role of human rights in that whole process and the fact that we have mental capacity law in order to protect people’s most basic rights. There is a real divorcing from what our human rights standards say and how that can work in practice. We see a lot of people who are quite confused by the MCA and what it actually means, and a lot of people working in safeguarding who are very familiar with concepts like best interests or dignity, but then are very confused about what that means in practice.

Actually, the work that we do in practice shows how you can use a human rights approach to drive that culture change forward and to say, “What we are talking about here is a way of giving unifying values, but also providing a framework to make some very difficult decisions in”. A human rights approach is how you look at the rights that people have, the responsibilities and duties that practitioners have, but also what that looks like in practice going through the way that you balance those different rights.

For us, we work quite broadly in the health and social care context, but also much more broadly with public bodies and officials. What we are seeing with the MCA is symptomatic of a much wider issue: that people just do not really know their basic rights, or their duties if they are a public authority. If we had that level of quite basic understanding, it would be much easier when we get into very specific practice-based settings around, “What we are talking about in the MCA is not something new or scary; it is about what those rights mean in this setting”. There is a basic building blocks thing that needs to happen, and that would make a lot of the implementation around the MCA a lot more realistic and a lot easier to grasp for a lot of professionals and practitioners, as well as for the individuals who should be at the heart of the Act.

Q187 Lord Turnberg: My question follows on from that. Whenever there is an Act of Parliament that depends on large numbers of people out there to implement it, I suppose it is inevitable that there is going to be a bit of variation in how that is enacted. I am sure that is one of the difficulties, and we are told that there are big regional variations in things like IMCA referrals and DoLS applications. What I am really interested in knowing is how you get the balance right between central directive and leaving it to local people to set it in motion and to do it. We do not always get that right. Local initiative is very important, but how much central direction do you need?

Paul Gantley: My experience would suggest now that there is something illusory about central control. My reflections would be you can provide the law, you can provide the code of practice and you can provide guidance, but that only really comes alive locally and it is only really implemented locally. The variations are a problem, whether it be IMCA referrals or the DoLS numbers, which in a way are the only numbers we have to look at in terms of this legislation, because the rest is kind
of abstract. They are a problem, but I am not sure it is a brand new problem in the sense that we often hear about postcode lotteries. Just for a point of comparison for myself, I was looking earlier in the week at last year’s Mental Health Act figures. I saw there that per 100,000 population, it was roughly 80 in London, 30 something in most of the country, and no one outside of London above about 50. To take the Mental Health Act, which has been around for a long time, you have more than twice as many people being admitted in London compared with most of the rest of the country.

**Lord Turnberg:** That might be the people.

**Paul Gantley:** There could be all sorts of reasons for that, but once you get into numbers the issue is that unless in advance or as things develop you set some kind of notional number as to what should be being achieved either locally or regionally because of variations you understand, it is all a bit of what I think/what you think.

One of the things that we were told when the deprivation of liberty safeguards were first coming into place was, “We’ve got very low numbers because our training has been so good”, and other people would say, “We’ve got very high numbers because our training has been so good”. Individual trainers would say, “If you look at where all the high numbers of activity are, it is all the places where I’ve trained the people”. That would be their CV’s USP. It is tricky. A postcode lottery seems to be inevitable, unless you have some quite sophisticated way of saying what the right figure is for that region. The fundamental answer to your question is that the real work is done locally in bringing about change and bringing about implementation and the centre can set the scene.

**Q188 Lord Turnberg:** We know of some places that do well by whatever measure. How do we spread that good practice?

**Paul Gantley:** That is key. This may be answering a slightly different question, but I think it flows, if you can just let me develop the logic. At the start, we were required to explain the law to people. It is a new piece of legislation, so you have to tell people what Section 4 or Section 44 is. We then realised that was not really doing it. Telling people what the law is is only getting so far because people only understand the law as they operate it. If you take this law, you have an untrained workforce in the care homes, a somewhat better trained workforce in other settings and a highly trained workforce in another setting. You then have family carers, all of whom are bound by the code of practice. To try to describe the law to all those people in all those environments is very difficult. Working with SCIE colleagues in particular, we discovered that we had to demonstrate the law in action. SCIE television for example starts to show how you make a best interests decision for someone in a care home around safety, or how you make decisions with people around finance.

One of the ways you have to do it in the end, whether it is nationally or locally, is you have to show it in action. You have to start from where the person is and then the law follows. The problem when you introduce a piece of legislation is that you start from the law, which in a way is the wrong way round in terms of trying to understand it for people on the ground.

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Patricia Kearney: Just to follow on from what Paul says, the data issue is not unique to the MCA. If you look at data around looked-after children in a local authority, does that mean it is a very vigorous local authority and very responsive to children’s needs or is it repressive practice that we are looking at? I think other people have said this: we do need some better and further analysis of the data that is coming in. Data are data, and you have to work out what it means in terms of variation.

Q189 I just want to say a little about how you embed learning following a pronouncement, a policy change or a law change. Our work on personalisation is an interesting model, because when we started off producing resources on that, people were saying, “This word is not in the dictionary”. We started with a rough guide, which explained why and what the concept of personalisation was, but we realised we had to follow that up with resources that said, “What does this mean for me?”. We have a whole range of small briefings for particular audiences—for example, people with autism and their carers, accident and emergency departments, safeguarding professionals—and then-emerging topics like personal budgets. How does this keep fitting in and being the underpinning and the centrality that drives an awful lot of other work in social care? I think we are just getting to the stage—where the codes of practice might be worth reviewing—of deciding whether we need to tease them out a bit more into specialist audiences and general audiences, if I can put it like that. Specialist does not necessarily mean an untrained professional and general does necessarily in this case mean a highly trained professional. It means, “This is not what I normally do”. So, in this context, accident and emergency departments, for example, might be considered a general MCA workforce, although highly specialised in their own daily practice.

Baroness McIntosh of Hudnall: This slightly anticipates a question we will come to later, but Mr Gantley, when you were embarking on this programme of implementation, was it any part of your team’s remit to think more widely than just the people who were going to have to implement the legislation and the people who were going to be directly affected by it? That is, did it strike anyone that a wider public health information campaign either was or might be necessary? If it did strike people, what did you do? It occurs to me that actually most of the discussion that goes on around this Act is focused on the people who are directly involved with it and very much less on setting it in a wider social context. If you compare that with the public health campaigns around things like HIV, it is understood that people are likely to be touched by the impact of that issue. Was there or is there any recognition of that in relation to issues to do with mental capacity?

Paul Gantley: I would say we became aware of that as things unfolded. Rosie Varley, who was the Chair of the Public Guardian Board, advocated that things like lasting powers of attorney and advance decisions to refuse treatment should be on the national curriculum. These should be things that teenagers think about early in their life. The Act was put into the kind of context that you are talking about. We certainly produced booklets that were distributed to be made available in GP surgeries and the waiting areas in local authorities. We produced material that was for the public. They would sit there to be picked up, but they were not aimed in the way that you say.

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Baroness McIntosh of Hudnall: You had to be in a surgery to get them.

Paul Gantley: Yes, precisely. There is certainly now a valid question and a potential task for public health professionals to pick up on. The Act is about planning for the future as much as it is one in which you lack capacity. That I think has not had as much publicity as it could have done. Off the top of my head, I think it was in 2009 that “The One Show” did a programme on lasting powers of attorney, and the Office of the Public Guardian was swamped the following week; there was a spike in applications. Periodically radio programmes such as “Money Box” and things like that have of their own volition looked at this, but it is a task that is still to be done.

Baroness McIntosh of Hudnall: We might come back to it later in the questioning.

Sanchita Hosali: I just want to pick up on a couple of the issues raised around centrality and guidance. On centrality, a lot of the practitioners and advocacy groups we work with do find the lack of centrally driven approaches to guidance quite difficult. There is a lot of local-level guidance explaining the MCA codes of practice, for example, and some of them are very good; some of them may be not so good. The issue then becomes to what extent it is actually legally accurate and reflecting the code of practice. That creates some very big concerns in terms of the postcode lottery and what is actually happening. While work does happen locally, there does need to be a level of central guidance driven home. Often groups and practitioners find they fall somewhere between the Ministry of Justice and the Department of Health because these issues cross over both of them. There is a little bit of: “Who is responsible for what?” The idea is that things do happen locally, but there needs to be some kind of centrality. The fact that there are variations can mean lots of different things, both good and bad, but the fact is there are variations, and that, in and of itself, is not a good thing.

Then on the idea of codes of practice, we had some briefing meetings and brought quite few groups and practitioners together. The thing that came out from those was the fact that the code of practice is so impenetrable, and it is very different from other types of codes of practice. It almost seems as though it is trying to be an explanation of the law as opposed to an explanation of what it means in practice. Some of the comparisons that the groups we worked with drew out were about equality law, where you have different types of codes of practice produced for different audiences. They include very practical examples of what that actually means and looks like in real life. That is a direction of travel that could be very helpful for the code of practice. Again, that is something that can be tailored for lots of different groups.

I would echo the importance of being relevant and starting with the person. As I said at the start, the whole point of this law is to protect the individual, but to protect their rights as well. It is not just protectionism; it is also ensuring that they can enjoy their rights and not have their rights restricted unnecessarily. It is really important to place that person at the heart of any issue to do with the MCA but actually being really practical and relevant about what that means and thinking about what in practice it looks like for those practitioners and how they balance a person’s...
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rights. For us, that is where a rights-based approach comes in to offer a framework to bring together all these things. The MCA is not operating in isolation, and often there is confusion with the Mental Health Act, where that comes in and how those two pieces of law sit together, as well as safeguarding policies and all sorts of things. It is thinking about what the approach is that is being taken across the board.

Q190 Baroness Hollins: Do you think the Mental Capacity Act presents unique challenges for implementation because of the wide range of professionals and individuals affected by it and, as Lady McIntosh has emphasised, the wide range of people who need to know about it? Are there any other similarly wide-ranging policies that we can learn from?

Patricia Kearney: I do not think it is unique. There are lots of examples of directives that directors have a wide audience, such as the Putting People First concordat. I would probably just expand that a bit to take up Baroness McIntosh’s point about the power of a public campaign. If you look at the dementia awareness campaign and how that fits in with all the dementia legislation and guidance, it is an enormous push. But sometimes the difference between professional and public perception is not always that wide. In fact, realising that what you are doing constitutes restraint or deprivation of liberty can come as quite a shock, whether you are the public, family carers and professionals. We found this out when we tested out our e-learning resources. The testing was really to see how the navigation works and whether you can move easily round the digital resource. There was shock from the professionals looking at the examples of deprivation of liberty and saying, “Oh heck. I do that”. The awareness works both ways, and we have learnt a lot from the implementation so far as to how to focus a public campaign.

Sanchita Hosali: I would agree with that. There are a lot of very good campaigns and programmes that have happened. We have mentioned dignity and dignity champions, and the dementia programme that is happening. These are all things in which there are some really good examples of good practice, but from our perspective working across the whole spectrum of health and social care, there are lots of things that are doing almost similar things, but not quite, and are very specific to the fields they are in. Rather than having an approach that looks at the whole person or the way health and social care is provided, we are focusing on dementia, but actually dementia has a huge element of the MCA attached to it. Dignity also has a huge part of the MCA attached to it. One of the things that we are quite conscious of is that there are lots of pockets of programmes, campaigns and activity that deal with isolated issues as opposed to looking at some of the much broader root causes, which those things could then sit alongside.

Patricia Kearney: If I could just add a quick supplementary to that, our resources and our training and consultancy have recognised that you have to start with a triangle of safeguarding, the MCA and dignity within a human-rights approach. When people see that triangle they think, “Oh, right. If I do one of those, , I am half way to the others”, and that actually they are part and parcel of the same thing. That is the ultimate message to get across.

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Paul Gantley: I would not claim it was unique, and clearly colleagues would contradict me if I tried to. What I think was a rare challenge, though, was the range of the number people who had to receive the information. That is unusual, in the sense that there was an ambition to try to communicate with all those eight million people, and that is difficult to do because they have such varying needs. If it is right that there are two million people today in England and Wales who lack capacity, there are many millions of decisions being made about those people. To try to contextualise all those decisions for all those people is a rare challenge.

The discussions are slightly about how you best set about communicating with that, which I think is a slightly different discussion. With the benefit of hindsight, I would say that you probably spend a bit less time on the law than you thought you had to and you spend more time on trying to find the entry or the in for the person who needs to understand the law. It is this inevitability of having to describe the law in the first place, if you are an implementation programme for a piece of law, that means it takes you a while to get the second stage. The second stage is a much more creative one in which you can communicate in a variety of ways. The first stage is frankly a bit dry, because you have to communicate facts about a piece of law. It is difficult to do that without simply stating the law and variations of it.

Q191 Baroness Browning: Mr Gantley, can I just ask about your experience from the Department of Health? People who are diagnosed with any condition very often say that having been to the hospital and got a diagnosis, whatever it happens to be, they then founder trying to find out about a condition. I know we have moved on and many hospitals have their own information desks and offices now, but this is a moving population so all the people who perhaps lack capacity today will be a different population perhaps from those who are seeking that information in two years’ time. Suddenly something has happened in their lives or their carers suddenly have responsibility. In the past, how has the Department of Health approached this dissemination of information to a moving population who will be quite different in the future from what they are today? This is not unique to the Mental Capacity Act. It is something that we have all thought about for a very long time.

Paul Gantley: For want of a better description, I think you have silos. You have policies on dementia or you have policies on strokes or something. People communicate almost through those diagnoses, so you have a campaign around dementia awareness or something. The problem with the Mental Capacity Act in that sense is that it covers all that. It is about all those things.

There was what struck me as a very sensible suggestion by the Nuffield Council on Bioethics a couple of years back—it might have been 2009, but I can find it if you want me to. They said that anybody who was diagnosed with dementia should be helped or encouraged to make a welfare power of attorney. That should be part of the discussion. Of course, whether they do or not is for them to decide. They went further. They said a lasting power of attorney should be free because it is a social good. That is a separate matter.

That is an example of extending the clinical interaction or the diagnostic moment into a wider thing around planning and around awareness: “Do you know?” You do not have to talk about the Mental Capacity Act at that point; you have to talk about
the things that you might need and they flow from the Mental Capacity Act. You could have the discussion even without ever mentioning the Mental Capacity Act. It is about that invisible, silent integration of these things into those moments, and we are a long way from that. I am not sure that those clinicians would see it as part of their role at the moment to help someone plan. Many will, but many will not. It is about that contextualisation of following the moment for someone.

**Baroness Browning:** Is this something that clinicians should focus on? One of the difficulties with a diagnosis, whatever it is—if someone is suddenly diagnosed with MS, for example—is that the clinician deals with the diagnosis; they do not necessarily give them the number of the local support group.

**Paul Gantley:** Yes, all that. You get into labelling and a social model of illness starts to include those things. A clinical model maybe does not veer beyond the treatment.

**Q192 Lord Swinfen:** The Government’s submission outlines significant training and guidance, and the Committee has seen a range of guidance produced by different organisations, yet we have heard significant evidence of widespread non-compliance. Can training and guidance achieve cultural change or is more needed?

**Sanchita Hosali:** Training is part of cultural change, but it is not all cultural change. That is something that we have seen that is quite problematic, not necessarily specific to the MCA but with the implementation programmes in general. You take a piece of law and you train on the piece of law, and then somehow it is reduced to training. I am not saying that is all that happened with the implementation programme. It is actually much more about an approach, and culture change takes a long time. It is not going to happen overnight. There are no magic wands—that somehow we have changed a culture. It is about looking at the ways in which we do change culture and testing what works, what does not work and finding out the ways in which we can bring those changes.

We have certainly seen some really positive results using a human rights-based approach to the organisation of healthcare service providers in the way rights are permeated, from top strategy down to service delivery, and what that service actually looks like in practice. That picks up from the previous point as well. An example of that would be our work with Mersey Care NHS Trust and the Learning Disability Directorate, and obviously a lot of what we are talking about has very particular meaning within that context. For the last few years, we have been working with them on what a rights-based service actually looks like. It is things like genuine empowerment and participation of service users in the process. It is not consultation; it is the creation of service user groups that are part of the process of hiring staff and investigating various incidents and part of the process of risk management and planning when there is a diagnosis, and the kind of information that is available. It is bringing in not just those individuals but individuals from across the whole staff team. It is clinicians, but it is also support staff and other people involved in that service as well as external independent advocacy and family groups, and thinking about an approach that brings all those groups together.

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The human rights framework can be very helpful in that, and we have seen some really good results from our evaluations of that work. We have seen it above 70% among staff, service users and carers that that kind of approach has been good for mental well-being, but it has also been good for changes in attitudes and behaviours, particularly among the staff team. It becomes about having a language to have conversations. We talk about people’s rights, but we also talk about duties and about ways to balance those in meaningful and practical ways. It does not become emotional disagreements and arguments. It does not become about different people’s internal moral compasses; it is a framework for approaching the whole process. We have seen some really good results with that, particularly in learning disability and mental health, which obviously has real resonance for the way people approach issues around the Mental Capacity Act.

Patricia Kearney: I would echo that. One of the issues is not just that we are moving into different populations but that a diagnosis does not automatically imply lack of capacity, or that there is lack of capacity today but not tomorrow and then back the day after. Fluctuating capacity is something that organisations and professionals really need to get their heads around. Rather than starting with the diagnosis and therefore a presumption about capacity—start with the liberty a person needs to have to enjoy their life.

Just to give you a quick example, one of our social care films is about Raymond and his money. Raymond is an 80 year-old person with dementia, and his main professional contact is a carer who comes in, and he wants to spend £50 on lottery tickets. (A lot of people would see that as an unwise decision, whether you had dementia or not!). The film shows how the process to make sure the five principles of the Mental Capacity Act is put into play by the carer: thinking about capacity, recording the decision and the process, and actually making sure Raymond gets to do what Raymond wants to do, and isn’t put at risk. That is a massive shift from wanting to keep people safe, -which is essentially proper and goodand you cannot take too much umbrage with people wanting to do that—to a very different way of regarding what the carer does and what the person using these services wants to do.

Lord Swinfen: How is this affected by the high turnover of staff, which we understand are often poorly trained as well as being poorly paid?

Patricia Kearney: There are two things. One is that the high turnover of staff in social care is an issue across a whole range of activities. I would not want to underestimate the difficulty of that. The CQC is looking more closely at induction training, for example, as a way to address what is part of a wider problem. We have found—and I think colleagues might say the same—that when we meet with frontline practitioners, there is often an instinctive wish to do good. When people start to understand what the MCA is trying to do, it makes sense. Then they are caught up in whether they have the right to make this judgment, which the MCA helps them with, and whether they are working in an organisation that is risk averse or risk enabling. All the issues about health and safety and so on play into those anxieties. It is something about how the organisation gives permission for staff, whatever level they are at, to work in a human rights way.

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Q193 Lord Alderdice: In a way, this slightly goes back to one of the things that Lady Browning was saying earlier. There is sometimes a tendency in a human rights framework in this context to see the rights being on the side of the patient or client and the responsibilities being on the side of the staff. In fact, though, there are responsibilities on the side of the patient and rights on the side of the staff. If Raymond decides to spend his £50 on lottery tickets, there are consequences. How far do you go in bailing him out of the consequences and how far do you not? There are issues of learning and so on. How do you work to ensure that the human rights culture that you are developing does not ignore the responsibilities on the side of the patient, the rights on the side of the staff and, indeed, of course both in respect of carers?

Sanchita Hosali: First, you have to be quite careful about using the language of responsibilities within a legal framework. You have to be clear about what we are talking about when we talk about legal duties and responsibilities, and moral obligations in the way we should behave and treat each other. Recognising that everybody in that situation has rights is a very productive starting point. Certainly, for the main part, the majority of our work started off working with practitioners and staff providing services. We have found that it is actually staff, particularly in middle management and frontline, who are very engaged by the human-rights approach. All of a sudden, it gives them something that is very practical and very realistic. It is the kind of thing that they can relate to because it relates to their values. However, it is also the recognition that they have rights as well in these situations. That can be quite a valuable move forward in terms of the culture change and process of bringing people with you. It is the recognition that all of us in this situation have rights and that there are different responsibilities, and that we need to make sure that all our rights are respected. That can be quite helpful.

Certainly, a big part of our work is about understanding what human rights really mean, and what they mean not just in law but in practice and relevance. That requires a level of expertise, experience and working together. It is not just off the shelf: “Everyone is going to understand human rights”. We recognise that that requires some work. Our practice work shows that if you take that approach of raising the capacity and awareness of each of those different groups that are involved in this situation, it actually becomes a framework that allows you to recognise everybody’s rights in that situation and to come to decisions that respect people’s rights.

For example, our work would look not just at the rights of patients and service users to access an outside space but at the rights of staff not to be subjected to bullying or harassment as well, and at the way that would fit into a framework to make sure that they are being protected. That is a really important part of the human rights approach. It is a human rights approach: it is all the humans in that situation. That is the staff and the service users, and the families and the advocates as well. The advocacy service is a really important part that goes back to that issue around culture change, information and who has access to those issues. It is also the idea that there are issues about making sure that there is independent advocacy and people have access to those services.
In a previous question, though, one of the issues was also around not just access to support groups but also who was commissioning these services. There is massively high staff turnover across lots of services, but what is the role of commissioners in addressing some of those issues? To what extent do commissioners use their power to ensure there are levels of knowledge and understanding within our various different services? I would say there is definitely huge appetite for learning. I would echo what Patricia said. People very rarely go into health and social care because they want to do harm to other people. It is often about reconnecting them with those values and what that actually means in practice. Certainly, we have held six events on the human rights approach to healthcare—three events this year. We were oversubscribed by about 120% because there just is not access to that kind of support.

Q194 Baroness Barker: Throughout our sessions, we keep bumping up against the lack of awareness on the part of the general public about this legislation, not just of the principles and all that but of the very practical stuff like lasting powers of attorney or advance decisions to refuse treatment. Given your experience, what sorts of things do you think could be done to change that? I did note your point about the civic education syllabus and so on.

Paul Gantley: Let me go back to the previous answer first. There is a role for people to disseminate some of that information as they go—to see their professional role as being wider than the immediate treatment or social care issue. The impact assessment for the Act talked about codifying the common law and that there would be no radical or wholesale change. That has not been the case. One of the successes of the Mental Capacity Act has been to muddy the waters a bit and to raise issues about what proper care is. Complacency would be too strong, but the situation was not as good as everybody thought it was. At its worst, people almost seemed to say that capacity or incapacity was kind of invented by the Mental Capacity Act, which is slightly odd. There is a wider role for all professionals in disseminating information as they go.

Other than that, again I mention Rosie Varley, who was the Chair of the Public Guardian Board. She thought there should be a Mental Capacity Act champion or champions to talk about these kinds of things. That is not to talk about the issues that professionals want to talk about, which is what deprivation of liberty is, or things that professionals are forced to talk about, but to talk about these wider advantages of the Act for people.

My own belief—and people at this point always mention “The Archers” or “EastEnders”, and I am not going to do that—is that if I do not know about it, what is going to convince me is to hear a compelling personal story that someone has: “In a moment of difficulty or crisis, it was really useful for us as a family to have a lasting power of attorney”, or, at the most extreme, someone had a good death as they wanted because their advance decision to refuse treatment was enacted. I think the answer lies in disseminating the experiences and stories of the people who are the ordinary members of public and the recipients of services. I do not think it is a matter for the professionals. I heard a consultant geriatrician who has a lasting power of attorney and has a personal condition of his own speak very compellingly of when he went into a crisis and into hospital; his lasting power of attorney was
used. He was a professional who knew all about the legislation, but the most compelling part of the story was the personal part. Something happened that he wanted to have happened. Somebody represented him. That is the story that needs telling. It is then a question of where you do that through the relevant articles, journals and the relevant media. I do not think it is a story for the professionals. It is a story for people themselves, for want of a better distinction.

Baroness Hollins: Do you think it is very widespread for members of the public to believe that they can make end-of-life decisions for their family members without a lasting power of attorney?

Paul Gantley: I do not think it is. There was a great deal of concern, as you and others will probably recall, through the passage of the Bill about these matters. The reality in the time since Royal Assent and coming into practice has been there have been far fewer of these. There is no momentum; it is a very unusual thing. If you talk to most healthcare professionals, they will say that it is something they rarely, if ever, come across.

Patricia Kearney: We get a lot of inquiries to our service from professionals and from the public—or their carers usually, rather than the public as a whole. First of all, that shows that the debate is still alive; implementation is not finished as far as people out there are concerned. Anecdotally, a lot of our queries from the public are around precisely these matters and the role of the Court of Protection and the Office of the Public Guardian. I know you are taking evidence separately about that. We find that the website is much clearer than it used to be, but people tend not to know about it. When we move them on to that, they find it very helpful, but why do they not know about it? We do not have the answer to that, but I think some very simple and straightforward publicising about the role of the Court of Protection would be very helpful—in supermarkets, for example.

Q195 Lord Swinfen: How do you ensure, when you have made a lasting power of attorney on end-of-life decisions and you are not well, that the people who are looking after you actually see that power of attorney and follow your instructions?

Sanchita Hosali: I would say that is why things like access to advocacy and independent advocacy are really important. I agree that we do need those personal stories in a much wider public and general debate about it. With these issues, we need our practitioners on the ground. We work in one particular mental health unit, for example, where there is one nurse who is very good at doing this but other nurses do not necessarily know about it. It is about those practitioners knowing, but also individuals having access to advocates who know these things, are there to support them to make these decisions, give them the information, and can then be the monitor of what happens in that situation.

Paul Gantley: One of the plans that I do not think has yet come to fruition in all the attempts to bring a new healthcare record into place was that each of us as individual patients would have something called “my personal space”, and that was viewed as the place where I would put the existence of my lasting power of attorney or the existence of my advance decision to refuse treatment. Somewhere else I would make it known that they were there. That was a technical or an IT solution

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to the problem. In the meantime, all that you can encourage is that, if I have one, it is something I must make known to my GP, for example, or somebody else. If I take the responsibility to make something, as things stand it follows that I must take responsibility to make it known to others.

**Baroness Barker:** Whatever they happen to think about it, professionals all seem to know not only what they have to do but what everybody else has to do to be compliant with the Mental Health Act. In stark contrast, we keep hearing time and again that while social care staff may well be compliant, there is a feeling that different professions, in particular medics, are not. What do you think can be done to deal with that?

**Paul Gantley:** I am a social worker by background. If we accept that in the first place, which is not necessarily a universal view, one of the things that social carers are often obliged to do at the start of a social care interaction is to work out whether there is a legal duty to do anything: whether someone has a legal right to a service or whether I have a legal right to intervene. Social care has a legal framework that sets the event in motion. The medical professions tend to rely in the first instance on trusted clinical practice, and I do not think their first instinct, whether it is an emergency or an elective moment, is to stop and ask whether there is an entitlement to this or, “If I do this, will there be legal consequences?”. Their instincts at that point are based on trusted peer clinical practice. There is a distinction in the way the law frames those two things, which might be part of the explanation for that.

At its starkest, a nurse said to me in a particular event, “If someone is on my ward, I will make a decision for them whether they lack capacity or not”. That is a cultural issue that says a lot. There is probably a more advanced culture of trying to reach a mutual agreement and something called empowerment in social care, broadly speaking. There is more of a reliance on knowing what the right intervention is and achieving that intervention for someone in a healthcare setting, just as a sweeping generalisation.

One of the reasons that often clinicians do not go through what they should go through, which is a proper consultation process and so on, is because they have already worked out what is going to happen in the end, because the right intervention for this person is treatment A or treatment B. In the worst case scenario, they are just busy and they think there is no point in going through the consultation: “It is not going to achieve anything because we already know what the outcome is”. It is the difference between what the law says you should do and what people do either because they are busy or because they know they are going to get to that place anyway.

It is how you get all the aspirations of the Mental Capacity Act, which are about how people should behave to get to that outcome, into practice when there is no incentive for those people to do that, because they are going to get there anyway. It is a cultural change to convince those people that it is a better world and that I receive a better service as a patient if I am involved in that transaction. It is how you achieve that culture change. You can only achieve that culture change through
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Q196 Baroness McIntosh of Hudnall: I think we have pretty much covered this, but I am just interested in it as a wrapping-up issue. You said something earlier on, Ms Kearney, about the moment that we are at with all these issues. You implied that we were very early in a process that was likely to be long and iterative. People have to learn and feed the learnt stuff into the process, and that then generates more learning. That is perfectly uncontroversial. However, are we doing this work too soon? You implied there just was not really enough evidence to know how this is all working. If we link that to the answer that Mr Gantley just gave about culture change and about how you get practitioners, whether they be medical or social work practitioners, to understand how to engage with this Act and to make it work, we are thinking, “Well, it has been five years. We ought to be seeing something happening”. Is that reasonable?

Patricia Kearney: I think it is absolutely the proper time to be shifting.

Baroness McIntosh of Hudnall: Good. That is a relief then.

Patricia Kearney: It is highly significant that our most recent publication resource about DoLS in practice has for the first time been able to put practice examples in because we are starting to get them. I think we should seize the moment. Data analyses, views of where good practice is happening and examples of that are starting to emerge. We should be looking for them vigorously, because the quickest way to get a culture shift is for me to see someone like me doing what I am being told to do.

Sanchita Hosali: I would absolutely echo that and agree with it. Now is absolutely the time to be doing this. As I said at the top, there has been such a disconnect between why we have the MCA and what it is all about. This is really timely to reconnect with that, but also to provide an avenue for the good practice that is going on, to get that message out there and to flag up where some of the issues are. While change and culture change is an ongoing practice, you cannot just leave it to continue in perpetuity. There will be points at which we need to stop and take a step back. With not just the big national scandals that we all know about but the local-level good practice work that is going on, now is the time to do that.

Paul Gantley: I would say that the Mental Capacity Act is a force for good and it has actually provoked some of these debates and some of these issues. Some of it is about whether people understand the law or not, but fundamentally to comply with the law is to behave well and to show best practice. The impact assessment said, “It sets out an expectation that best practice in attitudes and behaviour should be the norm for everyone”. We should still strive for that, but we need to show people what that best practice is. It is very difficult to make a demand of people that they are falling below best practice if we do not know what that best practice is. We need to somehow demonstrate to people what best practice is, and then that gives them something to strive for.
The Chairman: Thank you very much for your evidence. This concludes the public session and we will go into private session now.
1. The British Institute of Learning Disabilities (BILD) has worked for the last 40 years to ensure that people with learning disabilities are valued equally, participate fully in their communities and will be treated with dignity and respect. Within the sphere of learning disability, we provide services to develop the organisations who provide services, and the people who give support. Our aim is to make sure people are supported with dignity and respect and can make choices and decisions about their lives. For this reason we were involved in the development of the Mental Capacity Act, and are fundamentally interested in the manner and extent to which it has been implemented.

2. This response is informed by our ongoing contact with thousands of people with learning disabilities and the hundreds of organisations that work to support them, however we do not seek to speak for people with learning disabilities themselves. Rather we would prefer the committee to speak directly with people with learning disabilities and their family carers, and happily offer to host such an event.

To what extent has the Mental Capacity Act 2005 (MCA) achieved its aims?

1. The MCA has achieved its aims of providing a framework for decision making that puts the individual at the centre of the framework, enshrining in law that people’s diagnosis or condition should not be used as a determining factor in their ability to make decisions and in clearly stating that unwise decisions are not necessarily caused by a lack of capacity.

2. However, the understanding and implementation of the principles of the Act have not wholly met the aims which the Act sets out. Discrimination and assumptions of incapacity are still commonplace. In care settings it is too often the case that a lack of resources is used as an excuse to ignore people’s choices. The Act is all too often viewed as a framework of demonstrating that people do not have capacity, meaning that the instructions to support people to maximise capacity and take more control over their lives is all too often overlooked. If individuals are deemed to lack capacity in making a specific choice or decision, all too often they are denied further involvement rather than supported to be involved as much as possible.

At the core of the MCA are its principles and definitions of capacity and best interests. Are these appropriate?

3. The principles of the Act are good and much welcomed. Similarly, the definition of best interests given in the Act is very good. The centrality of the person’s wishes, beliefs, values and history within a best interest view is very good. However, all too often “best interests” is interpreted in a medical/paternalistic sense which is wholly at odds with that set out in the Act. For example, we are aware of situations where, in the name of their best interests, people have been denied access to their advocates because they were deemed to be “agitated” after meeting them.

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This appears to turn the definition of best interests on its head, whilst removing the one tool the person would have to challenge the decision.
To what extent have the five principles of the MCA been implemented in frontline practice? What evidence is available to assess this? Is there a satisfactory balance between enablement and protection?

4. The principles of the Act are being implemented into frontline practice, but they are a long way from established as yet. We would anticipate that implementation should lead to a change in culture that challenges those providing care and support to work in ways that assume capacity and values this approach. However, this does not seem to be happening due largely to a conflict with organisational cultures and issues of resources. For example, the ability to make unwise choices is continually tested against the desire of services to reduce risk.

5. Beyond this, there is a lack of knowledge and understanding of the duty to support people to make their own decisions. There are countless instances of this at an individual level. However, at a strategic and commissioning level it finds one expression in the fact that funding for independent advocacy (other than IMCA) has been declining at a sharp rate for the past four years. Given the number of examples in the Code of Practice where the involvement of an advocate is recommended to implement this principle, the current decreasing funding levels of independent advocacy should give the committee some cause for concern.

6. Most worryingly, it is not yet possible to say that the presumption of capacity and control is custom and practice. According to the Act, every adult has the right to make his or her own decisions and must be assumed to have capacity to do so unless it is proved otherwise. There are numerous examples where this is plainly not the case. Possibly the most striking is the fact that people still regularly report instances of 'Do Not Attempt Resuscitation Notices' on people's files without their knowledge or consent. This happens most commonly where someone has a mental health condition, a learning disability or is classed as an older person. This is an example of professionals taking a discriminatory and global approach to capacity to make decisions, it is directly in contradiction of the Act. In addition, particularly for individuals with with profound and multiple disabilities, there is often a lack of time spent getting to know the individual and their ways of communicating or to learn from those who know them best. It is often easier to presume a lack of capacity than to make a real attempt to empower them in terms of choice or decision making.

How effective was the Government’s implementation plan? What measures were taken to ensure that professionals and families of those who lack capacity know about and act in accordance with the provisions of the MCA? Has it led to sustainable change?

7. Although significant effort was put into the promotion of the Act, it is still not widely understood amongst health and social care professionals. Again, it is seen usually in relation to its framework for exerting control, rather than as a safeguarding and liberating force that could give individuals more control over their own lives.
8. For individuals and families, the picture is even less positive. Families are not generally aware of the Act until they come into contact with professionals who are using the legislation to increase their influence in decision making. Individuals and their families are rarely told about the Act in any proactive or positive way. Is the Act widely known and understood by professionals required to implement it? How does this differ across different sectors, such as health, social care, banking and others?

9. In the health and care sectors, the question is as much about whether there is a motivation to implement the Act as it is about knowledge. A lack of knowledge is often the assumed reason for poor implementation, however this seems unlikely. For example when looking at population adjusted referral rates for IMCA services across local authorities that use a shared safeguarding protocol, it is difficult to ascribe the wide differences in referral rates to knowledge alone. Is the Act widely known and understood by those who are directly affected by it and by their non-professional carers? To what extent does the Act provide protection and reassurance for informal carers? Has the right balance between protection of the carer and protection of the individual lacking capacity?

10. The Act has not been made sufficiently well known to individuals whose ability to make decisions might be compromised, nor to their unpaid carers. It is still essentially held as a part of professional culture. In this respect the Act has not ushered in the desired change in the culture of care. It could be argued that there should be a proactive duty to make people aware of their rights under the Mental Capacity Act. People can only utilise and exercise the rights of which they are aware. Has the role of the Independent Mental Capacity Advocate (IMCA) succeeded in providing a voice for clients and an additional safeguard against abuse and exploitation for those who have no-one to speak on their behalf?

11. The IMCA role has been a partial success. It has provided a safeguard and a greater voice for thousands of people in decisions that are fundamentally important, and this work is focused on those who have no-one else to speak on their behalf. However, low levels of referrals (particularly in relation to serious medical treatment) have reduced the impact that could have been made. In addition, there is some evidence that the willingness of IMCA services to challenge decisions and to be an active supporter of the person’s views is not robust enough in some areas. At its best, IMCA is a force for ensuring the dignity and rights of individuals who find themselves in contact with powerful and confusing systems, as exemplified by Hillingdon v Neary and highlighted in this excerpt from the judgment (123 &124):

“On 18 November, the IMCA delivered her report. It is an impressive document. For the first time, professional support was given to Mr. Neary’s arguments. The previous best interests assessments are subjected to analysis. The IMCA’s conclusion is that Hillingdon was potentially not acting in Steven’s best interests by refusing his father’s request to have his son live with him at home. The fact that this is the most important relationship in Steven’s life was noted. No evidence had been presented to show that the care he had given to Steven over the years was no longer appropriate. A return home, even as a trial period, should be considered. Further depriving Steven of his liberty might lead to emotional harm. Steven’s wish to return home was rational and understandable and Mr Neary had demonstrated in a number of ways
his willingness to work positively with professionals involved in providing care for his son.

This report pointed the way towards a different outcome for Steven."
Without the willingness and ability to provide a robust challenge, IMCA can be a mere rubber stamping exercise.

Has the level of referrals to IMCAs met expectations? What are the reasons for the regional variations in the number of referrals?

12. IMCA referrals are below what should be expected. Local implementation has varied and success has often been down to the willingness and commitment of MCA leads. However, a more serious and troubling variation lies in the difference of rates of referral between social care and medical agencies. The rates of referrals around serious medical treatment are still worryingly low, leading to the question of whether medical professionals are actually complying with their legal duties around the MCA. There seems to be no structure by which non-compliance with MCA is currently being highlighted or addressed.
Are IMCAs adequately resourced and skilled to assist in supported or substituted decision making for people lacking capacity?

13. Research in the advocacy sector suggests that over the past 4 years funding for IMCA services has remained level or reduced. In the same time frame, referrals to the service has increased significantly. This resource cannot be continually stretched without causing significant damage to the quality of service. It should be noted that the skills, knowledge and experience of IMCA providers in supporting decision making is relatively strong however there is some variability. Standards in this area must continue to rise, but for this to happen there must be both adequate resourcing and accountability.

Deprivation of Liberty Safeguards (DoLS) adequate?

14. DoLS are not working properly. One potential reason for this is that the decision making triggers for DoLS applications are administered by the same authorities who are likely to be most affected by their usage. It appears that this has led to gatekeeping and less use of the legislation than would be anticipated.

15. One potential option would be to place a duty on authorities to inform all people entering residential care settings and their families/carers of their rights in relation to liberty and of how to question and challenge deprivations of liberty. This would not differ greatly in nature or burden from the duty to inform people detained under the Mental Health Act of their rights.

Care Quality Commission

16. The Care Quality Commission could play a greater role in supporting the implementation of the Act if it were to take action on the results of its findings. It is welcome that CQC has made the duty to listen to those who use services central to its quality framework. However, there are numerous examples where inspectors would have found situations where the Mental Capacity Act was not being used appropriately and where there was little or no meaningful access to advocacy.

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services to support people’s decision making abilities. We are unaware of any action being taken in these situations. No care setting should be able to gain a satisfactory rating from a CQC inspection if it is unable to demonstrate how it actively supports people to be more involved in and in control of the choices and decisions that affect them. Without supporting people to do this, it is difficult to see how a service could possibly be treating people with dignity or respect.

3 September 2013
British Medical Association – Written evidence

About the BMA

The BMA is an independent trade union and voluntary professional association which represents doctors and medical students from all branches of medicine across the UK. With a membership of over 150,000 worldwide, we promote the medical and allied sciences, seek to maintain the honour and interests of the medical profession and promote the achievement of high quality healthcare.

Executive Summary

- Overwhelmingly, the experience of our members who have worked with the Mental Capacity Act 2005 (MCA) has been positive.
- Although the MCA extends far wider than medical decision making, there is a general sense that the MCA is clear, principled and, by comparison to some primary legislation, easy-to-use.
- The Code of Practice is likewise clear, practically-oriented and readable.
- The biggest single problem arising in relation to the MCA is a widespread lack of familiarity with it, both among health professionals, patients and those close to them. The BMA has produced guidance for doctors and other health professionals. Our MCA toolkit – a short, practical, pocket-sized guide – is available both in hard copy and online. Further efforts are required however to reach wider medical and lay audiences about this critical piece of legislation.
- The BMA would welcome an opportunity to explore the possibility of providing an exemption under the MCA to permit the testing of incapacitated adults where there has been a needlestick injury to a health professional and where such testing would not be directly in the best interests of the incapacitated adults.
- The BMA is concerned that the proper balance between protecting incapacitated adults and showing due respect for their prior autonomy may not be being achieved in relation to some decisions by the courts involving the withdrawal of life-sustaining treatment.
- The BMA has some concerns about the impact of the United Nations Convention on the Rights of Persons with Disability on treatment decisions involving adults lacking capacity.

Introduction

1. The BMA very much welcomes this opportunity to give evidence to the House of Lords Select Committee on the Mental Capacity Act 2005 (MCA). We fully supported the development of the MCA and we worked closely with what was then the Department for Constitutional Affairs during its drafting in order to ensure, as far as possible, that it reflected both medical reality and doctors’ fundamental ethical obligations both to respect autonomous decisions made by adults and to provide appropriate care and treatment to those unable to make decisions on their behalf. The BMA has not undertaken active research amongst its membership on the MCA. The comments that follow are based upon dialogue with both practising doctors and the members and representatives of BMA Committees over many years.

Specific areas of concern

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Needlestick injuries and best interests under the MCA

2. For many years now the BMA has received expressions of concern from doctors and other health professionals regarding the lawfulness of testing incapacitated adults for blood-borne viruses (BBVs), such as HIV, following needlestick injuries. Needlestick injuries are common in the NHS. Data collected by Public Health England identified 4381 significant occupational exposures between 2002 and 2011, increasing from 276 in 2002 to 541 in 2011. In 2010 a survey of the management of needlestick injuries from incapacitated patients in 226 intensive care units was undertaken. Over 60% of the units reported a needlestick injury from an incapacitated adult. Thirty six patients were tested for blood-borne viruses without consent. Sixteen patients tested positive for blood-borne viruses.

3. Under the MCA, the lawfulness of testing incapacitated adults solely for the purpose of benefiting a third party such as a health care worker is unclear. This extends to both the taking of a sample for testing, and the testing of an existing sample or one lawfully taken for another purpose. The BMA sought to have this issue clarified during the passage of the Bill but the Government at the time believed it to be unnecessary in the erroneous belief that it would always be in the best interests of the incapacitated adult to be tested for serious infectious diseases. This may not always be true, for example where the patient is imminently dying. It is sometimes said that in cases of risk Post Exposure Prophylaxis (PEP) should be started to manage the risk so testing the patient is unnecessary. PEP drugs can however have serious side-effects including diarrhoea and vomiting and can result in significant periods of absence from work. Where there has been a needle-stick injury there are therefore clear benefits to the health professional concerned in identifying whether the patient has a BBV such as HIV. The BMA raised this issue with the DH in 2005. At that time the DH explored the possibility of making regulations under the Human Tissue Act (HTA) permitting the taking of an existing sample, or one taken for another lawful purpose, in these limited cases. Because tests for blood-borne viruses are designed to be carried out on serum, and serum does not contain cells, it does not fall within the HTAs definition of ‘relevant’ material and so testing could not be covered by regulations under the HTA.

4. We recognise the significance of the concept of ‘best interests’ within the MCA and the vital need to protect the interests of vulnerable adults. In a 2011 legal case however the courts acknowledged that the concept of best interests need not be strictly confined to ‘self-interests’, and that a ‘best interests’ decisions ‘could result in altruistic decisions where the incapacitated person may on the face of it receive no tangible benefit from the decision’. The case related to the provision of maintenance to a family member and it is unclear whether an ‘altruistic’ best interests decision could be said to extend to someone with whom the individual has no direct private relationship. Research involving adults with incapacity nevertheless provides clear precedence, under the legislation, for an area of decision making, vital to the public good, in which best interests can, in certain highly controlled circumstances, and at no or only minimal risk to the incapacitated adult, be set to one side. The BMA would very much welcome an opportunity to explore the possibility of providing another exemption in order to protect health professionals who find themselves potentially exposed to serious infection in these circumstances.

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Best interests, end of life decision making and the MCA: is the Court of Protection giving too little emphasis to the prior wishes of once-competent patients?

5. The MCA was designed to achieve two main goals: firstly to ensure that adults are free to make all the decisions they are capable of; and secondly, where adults cannot make decisions, to ensure that decisions are made on their behalf on the basis of their ‘best interests’. The Act is designed therefore to have both an empowering and a protective role, and whenever its powers are used the balance between these roles will always depend upon the facts of the individual case. Prior to the coming into force of the MCA, the courts recognised that some medical decisions were so serious, or so ethically charged, that an application to the court for a declaration of lawfulness would be required before the action was taken. This remains the case under the MCA, and the Act’s Code of Practice lists a number of serious medical decisions that require court approval. Understandably, these will often include cases where, in the absence of legally binding authority such as an advance decision refusing treatment (ADRT), there is disagreement as to whether withdrawing life-sustaining treatment would be in an adult’s best interests. (Interestingly, the Code of Practice list of serious medical decisions were extended by the Court of Protection rules to include withdrawing life-sustaining treatment from adults in a minimally conscious state.)

6. A number of recent court cases involving treatment decisions at the end of life have raised questions about whether the proper balance between empowerment and protection under the MCA is being achieved in practice. These are highly complex issues. For the sake of clarity, we have outlined both the issues of concern and two of the legal cases in question. Should the Select Committee require it, we would welcome the opportunity to provide a more detailed briefing on these questions. The BMA will be holding a deliberative roundtable to further explore these issues in September this year involving senior clinicians, lawyers and ethicists.

7. The MCA makes use of a ‘best interests’ rather than a ‘substituted judgement’ model of surrogate decision making. It does not therefore seek to identify what the person would have wanted when he or she had capacity and give it binding authority. The Act is nevertheless explicit that relevant factors in making a best interests decision must include consideration of the person’s past wishes and feelings as well as their beliefs and values where these can be identified. Although in the absence of an ADRT, a person’s prior wishes may not therefore be determinative, they must be taken into account. From a medical perspective, a ‘best interests’ decision is therefore not solely a decision about what would be in the person’s objective clinical interests. It is much more nuanced, seeking to balance objective medical questions with far more subjective matters such as the individual’s underlying wishes and values.

8. In the court cases described briefly below – and in the judges’ written commentary – there is a question as to whether the balance between protecting incapacitated adults, and showing due respect for their autonomy, particularly where they had expressed prior decisions in non-legally binding form, has been properly achieved. These cases have involved the Court giving decisive weight to the prolongation of life – sometimes referred to as the principle of ‘the sanctity of life’ – even where patients had previously expressed views, albeit non-binding ones, that
they would be strongly opposed to active clinical interventions designed to extend their lives in such circumstances. Although we recognise the vital importance of this principle, in these and allied cases related to end-of-life decision making, the Court has given surprisingly little emphasis to the individual’s prior wishes, feelings and fundamental beliefs. (In non-medical cases the courts have emphasised that there should be a presumption in favour of respecting an incapacitated adult’s prior wishes ‘unless there is some potential sufficiently detrimental effect for P of doing so which outweighs this.’) In prioritising the prolongation of life, the court has, in our view, also given surprisingly little emphasis to a right or principle that will at times be in tension with it: the right to be free from inhuman and degrading treatment. In the cases below, both patients would be subject to sustained pain, indignity and discomfort, often for an extensive period.

9. We recognise that these are extremely complex, sensitive and ethically challenging decisions. Nevertheless, given the strong autonomy-promoting and protecting principles underlying the legislation, it is essential that the proper balance is achieved here. In addition, if the overall view is that the balance in these recent court cases is appropriate, it is vital that individuals who wish to influence decision-making at a time in their life when they may lack capacity are properly informed of the available options. They should also be made aware of the very strong emphasis that the courts are likely to give to the preservation of life, even where awareness is minimal and experiential pleasures are either nugatory or heavily offset by pain and suffering, should such decisions be referred to them.

Key cases

Re M

10. In February 2003 ‘M’, then aged 43, suffered viral encephalitis which left her with extensive and irreparable brain damage. After emerging from coma, she was diagnosed as being in a vegetative state. After several years exploring treatment options her family decided, with the support of the treating doctors, to apply for a court order to withdraw ANH. In the course of subsequent investigations it was discovered that M was not in a vegetative state but in a minimally conscious state (MCS). The family decided to proceed with the court application – without the support of the medical team – and the case was heard in the Court of Protection. Despite comments by M’s family to the effect that she would not have wanted to be kept alive in such a condition, in the absence of a binding advance decision refusing treatment or health and welfare attorney, the Court rejected the application and found in favour of the preservation of life. As the judge said in his commentary:

‘The various statements made by M prior to her illness in 2003 were informal and not specifically addressed to the question I have to decide. Accordingly, while I take those statements into account, they are not binding and in all the circumstances I do not consider they carry substantial weight in my decision.’

Although M had not made a formal advance decision refusing treatment in these circumstances, her former wishes were well expressed by her family. The Court set these to one side, giving determination to the principle of ‘preservation of life.’
Re E

11. E was a 32-year old woman who suffered from extremely severe anorexia nervosa. In April 2012 a decision was made in accordance with her wishes, the wishes of her family and with the full agreement of the treating team that further treatment was not appropriate and she was admitted to a community hospital under a palliative care regime. In May 2012, when her death was considered to be imminent, an urgent application was made to the Court of Protection by her local authority, asking for the case to be investigated. The judge concluded that E lacked the capacity to make decisions and that she had also lacked capacity at an earlier time when she had made advance decisions refusing the treatment in question. The court held that a sustained feeding regime, by force if necessary, would be in E’s best interests. In his summing up the judge said that although the competing factors were almost exactly in equilibrium ‘the balance tips slowly but unmistakeable in the direction of life-preserving treatment.’ Again, the principle of ‘preservation of life’ took precedence, despite it being likely that E would require force feeding for up to a year. E also testified that the experience of being force fed strongly reminded her of the childhood sexual abuse that was said to lie behind her disorder. In balancing the competing concerns raised by the case, in our view, it is surprising that the court paid so little attention to the right to be free from inhuman and degrading treatment.

The judgment can be found at: www.bailii.org/ew/cases/EWHC/COP/2012/1639.html


12. In its call for evidence the Scrutiny Committee has requested views on whether the MCA is compliant with the UNCRPD. Questions of legal compliance are outwith the BMA’s expertise. We would welcome this opportunity however to raise some questions about the Convention, in particular Article 12 – equal recognition under the law – and its potential impact on treatment decisions for adults assessed as lacking capacity to make specified decisions. Again, these are highly complex issues and for the sake of brevity we have limited our response to a few main questions. It is worth pointing out to begin with that knowledge of the UNCRPD is unlikely to be extensive among health professionals.

13. In our understanding the Convention makes no distinction – ethical, legal or practical – between physical and mental disabilities. Article 12(2) states that ‘states parties shall recognise that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.’ On the face of it this would seem to suggest that no individuals could lawfully be regarded as lacking in decision-making capacity.

14. From a clinical perspective, the matter of greatest ethical concern is the point at which it becomes morally permissible to make a decision on behalf of an adult. What are the criteria that need to be met by the ‘incapacitated’ adult before a decision by a surrogate can be said to be binding? To take an extreme example, presumably all relevant decisions will need to be made on behalf of an unconscious patient – excepting any binding prior decisions. Likewise a patient in a minimally

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conscious state would need to have decisions made for them. It is less clear however how clinicians should proceed where, for example, patients are in a florid psychotic state. Given that mental illness would amount to a disability, what would recognising the legal capacity of an individual who is in a severely psychotic state involve? Taken at its face value 12(2) could prevent health professionals making any treatment decisions on the behalf of adults, irrespective of the profundity of any cognitive or intellectual impairment.

15. We have seen that the MCA seeks a workable balance between promoting decision-making rights and offering protection to those whose ability to make decisions is impaired. The MCA also reinforced a decisive move away from ‘status’ or ‘output’ approaches to decisional incapacity. Neither the presence of a disorder or disability, nor the fact that someone makes decisions that are objectively regarded as poor could be taken by themselves as conclusive proof of incapacity. The BMA fully supported this approach, believing it to offer robust protection to the liberty rights of individuals, particularly those with disabilities. One of the questions raised by the UNCRPD though is what, in practice, equal recognition before the law means. Currently, in clinical practice, the presence of decisional incapacity does lead to a change in legal status. The adult’s legal ability to consent or refuse treatment is set to one side. The UNCRPD could therefore have a significant impact on the provision of care and treatment to people suffering from severe cognitive and intellectual disorders. The BMA would very much welcome the opportunity to discuss this in greater detail with the Committee.

Independent Mental Capacity Advocates (IMCAs) and serious medical treatment

16. We have already mentioned that knowledge of the requirements of the MCA is not as extensive as it should be. The BMA has, from time-to-time, received expressions of concern from health professionals about the advocacy provisions under the MCA. The main areas of concern include:

17. Overuse of the IMCA provision. This has involved enrolling or requesting the use of IMCAs to make trivial or inappropriate decisions, or requesting or enrolling IMCAs in circumstances where there are other people whom it would be suitable to consult.

18. Managing disagreement between IMCAs and health professionals. Doubt has been expressed about the extent to which IMCAs see their role as advisory or as far more active decision makers. Further advice on managing disagreement between IMCAs and clinicians would be helpful.

19. The definition of serious medical treatment. There will be occasions when there will be, as the Code of Practice says, ‘a fine balance between the likely benefits or burdens’ of the treatment, or where ‘the decision between a choice of treatment is finally balanced,’ but the treatment in question will not have serious consequences for the patient. In these circumstances, enrolling an IMCA would appear to be excessive in relation to the risks involved. Although the Code goes on to say ‘or what is proposed is likely to have serious consequences for the patient,’ it would make more sense to have this as a necessary condition for all IMCA involvement in medical treatment, otherwise there is a risk of enrolling IMCAs for large numbers of trivial decisions.
The deprivation of liberty safeguards (DOLS)

20. The BMA recognises the importance of ensuring that any deprivation of liberty involving an incapacitated adult must be kept to an absolute minimum. Given the restriction of fundamental rights involved, we also recognise the need for some kind of oversight of care or treatment that involves, or amounts to, a deprivation of liberty. The DOLS were introduced to ensure compliance with the European Convention rights and to plug the so-called 'Bournewood gap' which involved the de facto deprivation of liberty of an autistic man with profound learning disabilities.

21. The primary concern with the DOLS is their complexity and bureaucracy, as well as the difficulty of identifying, in some circumstances, whether a deprivation of liberty has taken place. The BMA would welcome a streamlining of DOLS and further guidance for health professionals on what kinds of care amount to a deprivation of liberty.

References


Re: G(TJ) 2010 EWHC 3005 (COP)

Re: S and another (protected persons) [2010] I WLR 1082.

22 August 2013
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About the Society

The British Psychological Society, incorporated by Royal Charter, is the learned and professional body for psychologists in the United Kingdom. We are a registered charity with a total membership of just over 50,000.

Under its Royal Charter, the objective of the British Psychological Society is "to promote the advancement and diffusion of the knowledge of psychology pure and applied and especially to promote the efficiency and usefulness of members by setting up a high standard of professional education and knowledge". We are committed to providing and disseminating evidence-based expertise and advice, engaging with policy and decision makers, and promoting the highest standards in learning and teaching, professional practice and research.

The British Psychological Society is an examining body granting certificates and diplomas in specialist areas of professional applied psychology.

Publication and Queries

We are content for our response, as well as our name and address, to be made public. We are also content for the House of Lord’s Committee of the Mental Capacity Act 2005 to contact us in the future in relation to this inquiry. Please direct all queries to:-

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We hope you find our comments useful.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
David J Murphy CPsychol  
Chair, Professional Practice Board  
British Psychological Society response to the House of Lords Call for Evidence  

Implementation of the Mental Capacity Act 2005  

Introduction  

The British Psychological Society (the Society) thanks the House of Lords Select Committee for the opportunity to respond to this consultation. The Society would welcome the opportunity to address the Select Committee on some of these issues. Practitioner Psychologists work in all areas where people may lack capacity – learning disabilities, older people’s services, neurological, mental health and forensic services. Assessing, enhancing and working with capacity issues is a core part of psychologists work. 

The Society contributed to the consultation on the 2005 Bill and has been involved in the development of the Code of Practice and the Deprivation of Liberty Guidelines. The profession has also produced guidance on Assessment of Capacity (2006), on Best Interest Assessment (2007), an Audit tool for Mental Capacity assessments (2011) and on Research involving people who lack capacity (2011). 

The Society has a working party that produces guidance for its members. The working party produces guidance relating specifically to the Mental Capacity Act 2005. 

This response is based on the extensive clinical experience of working with the mental capacity act both directly with individuals and families, but also in working in service settings where it is possible to evaluate the impact of the act on culture and practices. 

Overview and context  

To what extent has the Mental Capacity Act 2005 (MCA) achieved its aims? 

1. Comments: 

The Society believes that when the Act is used as it should be, it provides a helpful and comprehensive framework with regard to capacity and best interest providing explicit principles and clear guidance for putting these into practice. It has clarified the legal position and the role of the law within capacity issues. It has illustrated well the need to balance care and protection against empowerment and the individual’s right. However there are still services where knowledge and application of the Act is limited.
Most people working in health and care services have some knowledge of the act. In most services, people are now more mindful (or at least correct processes can be pointed out when there is a failing) of that fact that:

- Mental Capacity needs to be a core consideration in work with any vulnerable group or individual
- That a paternalistic approach is not acceptable as a basis of care decisions
- Capacity needs to be considered as opposed to ‘it’s their choice’.
- If people do have capacity then we need to respect their choices

However in many areas there is still a ‘long way to go’ in relation to care provider’s interpretation of the act and of the best interests process and its implementation. The Society recommends that there should be clarification of the code of practice in the light of experience with a new edition being commissioned.

Areas that are of particular concerns are:

1. General medical in patient services and
2. Third sector provision of 24 hour care services for older people and people with Learning Disability and with Acquired Brain Injury (ABI).

Which areas of the Act, if any, require amendment; and how?

2. Comments:

1. Psychological factors impacting on capacity

Clarity around when emotional/mental health issues impact on decision making (e.g. someone who has a history of severe neglect, multiple abuses, difficulty in asserting their needs, despite having adequate financial knowledge, gives all of their money away). It would be valuable if any amendments to the Code of Practice should specifically address this. The Society has particular expertise in this area and is willing to contribute.

2. Undue Influence

There needs to be increased clarity around the concept of ‘undue influence’ and to what degree this would need to be at in order to render a person incapacitated. It also needs to be clear as to how ‘undue influence’ could be evidenced. It would be valuable if any amendments to the Code of Practice should specifically address this. The Society has particular expertise in this area and is willing to contribute.

3. People with Dysexecutive problems/Serial poor decision makers

There are examples of people (for instance those with ABI) who are able to demonstrate capacity within an assessment but lack the capacity to maintain this in practice due to cognitive impairments. Problems with “executive functioning” are often not identified within routine capacity assessments but can lead to risky behaviours for self and others. It would be valuable if any amendments to the Code
of Practice should specifically address this. The Society has particular expertise in this area and is willing to contribute.

4 Decisions beyond Day to Day Care

The Society has concerns about the lack of accountability for decisions made under the MCA, given that there are no formal procedural requirements nor audit procedures. For decisions beyond day to day care, we would recommend that decisions should be formally recorded (as opposed to the expectation they will be recorded).

5 It would be helpful to have greater guidance on what constitutes Serious Medical Treatment

6 Capacity to Consent to sexual relations.

This is explicitly excluded in the Act but there is currently considerable confusion about this area and examples of where services have used the MCA as a reason to stop two people with LD from being able to have sexual relations.

The Society is currently finalising guidance on this area, but it would also be of value if clear legal guidance could be produced in this area.

At the core of the MCA are its principles and definitions of capacity and best interests. Are these appropriate?

3. Comments:

These are well considered, expressed and remain appropriate.

The Society would propose that the area of psychological factors impacting on capacity and undue influence might be included in any revision.

Implementation

To what extent have the five principles of the MCA been implemented in frontline practice? What evidence is available to assess this? Is there a satisfactory balance between enablement and protection?

4. Comments:

At a general level, it is understood amongst qualified professionals. However there are still deficits in people’s knowledge of the Act, and its implementation.

- There is still over-reliance on seeing an expression of a preference, or a ‘want’, as capacity (leading to, for example, people without capacity being allowed to become hugely obese, to the point of health risks).
- In other settings, particularly general medical inpatients wards, there is still a tendency to act in a paternalistic/authoritarian fashion and make decisions based on
the staff’s perception rather than going through the procedures of implementing best interests.

• Not enough attention is paid, at times, to the persons’ ability to ‘weigh up’ the evidence as part of the assessment.

• Clarification that the decision is made on the balance of probability would be helpful i.e. only need to be 51% sure a person lacks capacity not 99.9%.

• Services struggle with the person’s right to make unwise decisions, especially where risk is involved, leading to people’s rights being restricted.

• Banks, phone companies, loan companies etc are still giving credit, insurance policies, etc. to people who clearly lack capacity.

• It is seen by many professionals as complicated and as an onerous task. Some, who are used to making independent decisions, find it hard to adjust to the requirements of the MCA (2005) and best interest requirements of consulting with other people involved with the individual e.g. prescribing medication for someone with dementia.

• People with learning disabilities and their families do not have good knowledge of the Act or their rights under it.

How effective was the Government’s implementation plan? What measures were taken to ensure that professionals and families of those who lack capacity know about and act in accordance with the provisions of the MCA? Has it led to sustainable change?

5. Comments:

The Society’s view would be that implementation has worked well when key people were identified within the organisation and there was a clear lead from within an organisation (usually the Local Authority) and especially if there was a multi-agency lead group.

The initial focus for qualified professionals was good.

We are less confident that the same attention was given to families and informal carers.

For several years after the introduction of the Act there were resources to provide small project funds to support the implementation of the Act. The Society was able to receive funding to produce further guidance from SCIE on Best Interest procedures (2007), Standards for Assessment of Capacity (2011)(evaluated by McBrien et al, 2011) and on Research (2011) from the Department of Health. These publications were highly commended outside of our profession and this type of resourcing maintained interest in and confidence in using the Act.

The Society would consider that the implementation has led to change in the culture of care; however the focus has now shifted away from capacity issues. The Society would recommend that it there should be another trench of work informing people about the Act, clarifying areas of implementation and enhancing skills, in order that knowledge of the Act be disseminated, and more widespread implementation and better systems for monitoring and accountability are achieved.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.

Is the Act widely known and understood by professionals required to implement it? How does this differ across different sectors, such as health, social care, banking and others?

6. Comments:

The Act is widely known and understood by qualified professionals within health and social care and systems for implementing it at a systems level appear generally robust, although in practice the implementation and monitoring is less effective as demonstrated by the audit described earlier.

There are specific issues within some areas of Local Authority responsibility, e.g. people who lack capacity to manage finances often are supported by the Local Authority Deputyship Team. This is an overworked, under-resourced team, made up of staff (often very junior) who have no training in dealing with people with learning disabilities and/or mental health problems, so they are often unable and/or unwilling to do the work required to involve people in decisions about their finances. There is a governance issue and we would recommend clarification of responsibilities, expected competencies and procedures.

In areas that relate to finance, banking, retail etc, there seems to be little interest in understanding the principles of the Act nor in changing practices to address this issue. Examples of people with learning disability taking out unviable hire purchase agreements, of older people with dementia entering into contracts via phone conversations or door to door sellers abound. Whilst this is clearly a highly complex issue and does raise considerable moral dilemmas in relation to autonomy and the right to make unwise decisions, nevertheless a legal clarification of the provider of service’s responsibility to make an assessment would at least reduce the worst examples of offences. It may be helpful to clarify that if a person lacks capacity to make financial decision then the contract would not be valid.

The areas of acute medicine in general hospital settings are of a particular concern and it is recommended that there should be a particular focus on this in any future development work.

Is the Act widely known and understood by those who are directly affected by it and by their non-professional carers? To what extent does the Act provide protection and reassurance for informal carers? Has the right balance between protection of the carer and protection of the individual lacking capacity?

7. Comments:

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There appears to be wide variation across the country and whilst there are examples of excellent practice, there are many examples of where informal carers lack the knowledge and understanding of the Act, their role and rights within it, and how to ensure that this is included in care planning.

Much of the responsibility for this lies with social services but all services and professionals would be expected to support informal carers in a timely fashion; this could be strengthened, for instance in memory clinics for those first diagnosed with dementia.

The Society suggests that it may be valuable to ensure that those who work with carers as they start to interface with services, perhaps at an early stage, are informed and empowered to play a role in informing them about the MCA and its procedures, GPs and staff within primary care, such as community nurses.

Has the Act ushered in the expected, or any, change in the culture of care?

8. Comments:

The Society’s view is that the Act has improved the culture of care, especially for those who are most impaired and therefore most vulnerable.

However, the Society believes that this could be strengthened and in particular be consolidated in areas where this has not made sufficient impact; one such would be district general hospitals and acute medical care.

Is there any evidence that the provisions of the MCA affect some groups disproportionately? If so, what data exists to compare representation across different socio-economic groups, Black and Minority Ethnic groups, and gender?

9. Comments:

The Society has no comment to make.

Decision-making

Are those directly affected by the Act being enabled and supported to make decisions for themselves to a greater or lesser extent than they would have been in the past? Does the means by which the decision is made – ‘general authority’, Lasting Power of Attorney, deputyship, Court of Protection – affect the quality of decision making?

10. Comments:

The Society believes that the changes have been influential at a general level and lead in many areas to significant improvements in decision making. The Court of Protection has been particularly influential. However, it would consider that there are also many situations where there is no change.
The Society considers that it might be timely to review and clarify the respective roles within the area of decision making and produce amended guidance in the light of experience.

The Society is concerned that there is currently no requirement for proactive scrutiny or audit of these processes and it is therefore dependent on individuals to raise concerns and complaints. We would recommend that this area be strengthened.

What evidence is there that advance decisions to refuse treatment are being made and followed?

11. Comments:

The Society has little evidence about this but has been aware of situations where there is a lack of understanding of Advanced Decision to Refuse Treatment (ADRT) and other related procedures, such as Do Not Resuscitate (DNR) statements. There may be a conflict in hospitals and care homes between the role of those with Lasting Power of Attorney (LPA) for Health and Welfare and DNR arrangements.

We recommend that clearer guidance is provided within these areas.

Has the MCA fostered appropriate involvement of carers and families in decision-making?

12. Comments:

The Society believes that this has improved and there are examples of excellent collaborative working in many areas. However there are also areas where this remains unchanged.

Has the role of the Independent Mental Capacity Advocate (IMCA) succeeded in providing a voice for clients and an additional safeguard against abuse and exploitation for those who have no-one to speak on their behalf?

13. Comments:

The Society would state that from experience, the role of the IMCA has been generally an extremely positive one and there are examples of where they have supported the individuals in setting where there is a risk that their views and wishes are not being respected and being able to challenge those in authority. IMCA’s have been a useful voice, and are seen as exercising some power. Their understanding of the issues is becoming more sophisticated.

Has the level of referrals to IMCAs met expectations? What are the reasons for the regional variations in the number of referrals?

14. Comments:

The Society has no comment to make.
Are IMCAs adequately resourced and skilled to assist in supported or substituted decision making for people lacking capacity?

15. Comments:

The Society has no comment to make.

Deprivation of Liberty Safeguards

Are the safeguards in the Deprivation of Liberty Safeguards (DoLS) adequate?

16. Comments:

A number of Society members are trained to take on the role of Best Interest Assessment (BIA) under DoLS and thus have direct experience of the system. From this and the clinical experience more widely there are the following comments in relation to specific areas.

1. Within supported living There has been a huge shift towards this arrangements even for very severely impaired people, and staff are not able to use the DoL safeguards as the homes are considered to be the person’s own home and DoLS does not apply in this setting. Any deprivation in these settings needs to go through the Court of Protection which is a more prolonged and more costly route that local authorities are less likely to pursue. Therefore, there is a risk of there being an inadequate legal framework to provide the care as determined by risk assessments.

2. People in residential care who are self-funded The Society is aware that people who are in residential care and who are self funding may not be identified as being at risk of deprivation of liberty, if the managing authority does not identify this as an issue and if there is no active involvement of family or friends and no Social Services involvement. We have had examples where visitors from the Local Authority or Health services have incidentally identified other residents who appear to be deprived of their liberty. We would recommend that the CQC should include this as part of their inspection and review mechanism.

3. There is serious variation across regional areas and individual BIAs as to what constitutes a deprivation which is extremely unhelpful. Greater national guidance on this would be extremely helpful which is updated in the light of new case law regularly. At the moment there is no clear way that all services keep themselves up to date with these issues.

4. The Society has a particular concern that the Cheshire West case, if upheld, would restrict access to the protection of DoLS of the very client group that require its protection. The implication of that decision is that severely impaired people requiring complex management, should be outside of DoLS as this would be considered ‘normal’ for their condition.

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British Psychological Society – Written evidence

We are aware that it is being reviewed in the Supreme Court in the autumn. However it illustrates the dangers inherent in dependency on case law, as this can lead to confusion and contradictory BIA decisions whilst waiting for clarification.

Are the processes for authorisation, review and challenge of DoLS sufficiently clear, accessible and timely?

17. Comments:

A number of Society members carry out this work and are able to feedback from their experience. The procedural system of carrying out a BIA under DoLs appears to cover all issues well and appears to balance the rights and protection for the individual with the protection of staff in carrying out their care role.

We have three comments:-

1. The paperwork is unduly bureaucratic and repetitive, specifically -
   • The Mental Capacity form could require more explicit justification for the decision, perhaps using the four headings as prompts.
   • The MH and Eligibility forms could be combined into one.
   • The Age form could be included in the main Assessment.

2. There could be clarification of the interpretation of the mental health and eligibility criteria.

3. It is recommended that there should be clarification of the role for supervisory bodies in reviewing ‘rolling DoLs’, DoLs that are re-authorised repeatedly, especially when the Court of Protection is not involved to provide oversight.

The Court of Protection and the Office of the Public Guardian

Are the Court of Protection and the Office of the Public Guardian sufficiently understood and accessible to all? Are they operating effectively and successfully?

18. Comments:

1. The Society would view the role and activity of the CoP and OPG as good examples of the overarching role of the law in ensuring the balance between protection and care, and in clarifying the roles of carers and statutory services. In general it appears to work well.

   It appears to be well understood but this will require a longer time scale and more experience to be able to clear about this.

2. However accessibility appears to be an issue.
   • The CoP has been overwhelmed by referrals and therefore waiting times are too long for more routine cases.
   • There is a particular impact of Court of Protection under- resourcing, particularly regarding its financial decision making cases, which can take longer than

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six months to be resolved. For example, someone newly brain injured will need to arrange their financial affairs sooner than this process is currently taking. It is having a real impact on families and on discharge planning.

• Due to capacity issues, it can be difficult to find local authority appointed people to act as Appointees or Court Appointed Deputy, etc. in a timely fashion.
• Families can be confused and overwhelmed by this process. The associated costs of applying to the COP decreases the likelihood of families, professional care providers, health and social care to take that course of action.

3 Tenancy agreements are a particular issue. If a person lacks capacity to sign a tenancy agreement then there is potentially a long wait to go through the Court of Protection. This is in conflict with the Social Care Act which is a driver to increase tenancy agreements for individuals. The Society recommends that there should be some clarification in the implementation of the Act so that tenancy agreements could be considered as part of the best interest process. This would free up the COP, increase the speed of the process and increase compliance with the law.

4 It is extremely difficult to get a health and welfare deputyship (except if you have an LD it seems where the trend is the opposite). They are often rejected on the basis that the main principles of best interest should apply and decisions should be made under section 4 or single orders. The Society recommends that this area be clarified.

5 The Society is aware that there is consideration of some mediation provision to allow an earlier resolution process when matters are currently taken to the CoP. We would generally support this but with a caveat that is should be one form of dispute resolution and not an alternative to the access to the CoP.

What has been the impact of the introduction of Lasting Powers of Attorney (LPA), especially with regard to decision making on matters of personal care and welfare?

19. Comments:

The Society has no comment to make.

What concerns, if any, are there regarding the costs associated with registering an LPA, or with making an application to the Court of Protection?

20. Comments:

The Society considers that Lasting Power of Attorney arrangements should ideally be completed by all adults in advance of aging and infirmity to provide a safeguard in the event of loss of capacity. The forms and processes should therefore be amended to make this an easy and inexpensive thing to do.

The LPA forms are un-necessarily long, bureaucratic and poorly structured. They are difficult for a non-legal trained person to complete correctly, although the CoP staffs do provide excellent support and advice when it is completed by lay people.

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The Society would recommend that the paperwork be streamlined such that there is a system that does not require the employment of a solicitor to be completed satisfactorily in straightforward situations.

The Society would also recommend that there is more public guidance about the cost of preparing these forms and who has to pay. Some solicitors, we are informed by families, are charging high fees. Families are unclear who should pay – them or the person and how to request a waiver.

Is legal aid available and sufficient? What impact will the recent and proposed reforms to legal aid have?

The Society is aware from clinical areas of concern challenges taken to the Court of Protection by family carers, e.g. Neary, rely upon legal aid and would be concerned that the recent Government reforms will result in challenges like this becoming less frequent and therefore people’s rights being potentially breached much more easily.

The Society also has a concern that the cap on expert witness fees will also result in less access to expert professional opinion in the case of legal challenge.

Is the role of the Care Quality Commission in inspecting on the MCA standards adequate and appropriate? Is there a case for additional powers?

The Care Quality Commission has already initiated changes in the wake of investigations and court cases to ensure that it is able to provide more intensive investigations in care settings where capacity issues are pertinent. The Society would support this and encourage it to ensure that there are sufficient on site visits, sufficient time to directly observe care practices and to ensure that anyone with concerns is able to raise them confidentially (both residents and staff).

Should other regulatory bodies, such as health and social care professional regulators, be acting in this area?

All regulatory bodies should be acting in this area to ensure at a general level that their members are knowledgeable and confident in using the MCA and its procedures.

They should take action in relation to individuals to ensure they meet their professional and ethical obligations.

Other legislation

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How well is the relationship with the mental health system and legislation understood in practice?

24. Comments:

There is an ongoing ambiguity and confusion about the relationship which impacts on staff, particularly in patient wards. The uncertainty is partly as the actual distinction is determined by case law, which will develop over time.

It is partly because while it is often stated that the MHA ‘trumps’ the MCA this is incorrect as it depends upon the particular issue in question. However in relation to, for instance, a person with dementia on an inpatient ward waiting for discharge to a 24 hour placement, there are currently different views. The Royal College of Psychiatry has issued guidance that is contradicted by those working from the legal perspective. Staff can be left in the middle – unsure about their legitimate use of holding powers.

The Society would recommend that there should be clarification of the mutual roles of the two Acts and that the DoH should work with professions to produce a jointly agreed decision tool to assist in the implementation.

Devolved administrations and the international context

Does the implementation of the Mental Capacity Act differ significantly in Wales?

25. Comments:

The Society has no comment to make.

What lessons, if any, can be learnt from the approaches taken to mental capacity legislation in Scotland and Northern Ireland, or in other jurisdictions?

26. Comments:

Northern Ireland’s legislation is not in place yet. The England 2005 MCA drew on the experience from the legislation earlier passed in Scotland but there were at least two very important differences.

Firstly the Scottish Act was an Incapacity Act, whereas the English Act was the Mental Capacity Act, and this shift of focus runs through the legislation and its implementation.

Secondly the English Act incorporated a set of principles that identify the underlying philosophy supporting the Act.

Is the MCA compliant with the United Nations Convention on the Rights of Persons with Disability (CRPD)? Are there lessons that can be learnt from the CRPD for the successful implementation of the MCA?
27. Comments:

The Society has no comment to make.

3 September 2013
Browne Jacobson Solicitors LLP – Written evidence

Introduction

1. Browne Jacobson LLP is a law firm with a national leading health and social care practice, and responds to the House of Lords consultation with the benefit of views expressed by a number of our clients across the health and social care sector.

Overview

2. The MCA is a good thing. The principles are important and clearly drafted, and it has had some success in raising awareness of the key issues and the competing principles of empowerment / protection of autonomy on the one hand, and safeguarding / protection of the vulnerable on the other.

3. Where criticism is made of the MCA, it often reflects frustration about its implementation and application in practice rather than disagreement with its fundamental basis or principles.

4. Rather than wholesale revision or reform (with the possible exception of the DOLS), we would encourage greater focus on the consistent implementation, and resource to improve training, and support sharing of experience and application in practice.

5. We would, however, have advocated that it not be called the “mental capacity act”, but rather the Capacity Act, (or even the “making decisions act”, perhaps), to reflect its universal application, and minimise what ought to have been avoidable conflation with the Mental Health Act.

Implementation

6. On the positive side, the MCA has raised awareness of capacity issues, but there is often frustration that it hasn’t been implemented as effectively as it could have been. The withdrawal of the central funding and regional support was felt to have hindered consistent implementation.

7. Often where regional networks or other means have been developed to promote sharing of knowledge / experience, these have been ad hoc, unfunded or supported by organisations as a matter of goodwill.

8. Lots of training has contributed to greater awareness, but often it is felt that this has been at a fairly superficial level – still telling people what it says, not what it means, or really addressing the difficulties with implementation in practice.

9. Some feel that training has been arranged as a tick box exercise, and it doesn’t help that it is often not quality assured. For example the statutory, mandatory DOLS refresher training does not carry any benchmarking or assurance as to either content or quality.

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10. It is not clear that mandatory annual refresher training is sufficient for DOLS assessors (or anyone working with the MCA) to keep up to date with the fast moving case law produced in the Court of Protection, and so among other resources we have been producing quarterly webinars free of charge covering MCA / DOLS case law updates – see www.bjlegaltraining.com.

11. Implementation of MCA and DOLS is inconsistent across organisations, and across disciplines within organisations, often reflecting the cultural background of the organisations / professions, and their traditional structures and hierarchies.

12. Among healthcare professionals generally, our clients felt that awareness of capacity often does not yet carry the same weight that is given to “consent”, despite the fact that without capacity there can be no consent.

13. It remains the case that capacity is more often challenged where there is non-compliance with a clinical recommendation. Conversely, compliance is sometimes considered a proxy for both capacity and consent.

14. In implementation of the basic principles of the MCA:-
   • the inherent contradiction between those principles promoting autonomy, and those promoting protection is easily overlooked.
   • Those principles which are more in keeping with traditional approaches and attitudes in healthcare in particular – eg acting in a patient's best interests – have been most readily accepted and gained the most traction in practice. However, there is still a temptation to start with action “in best interests”, before real consideration is given to capacity, or to taking all practicable steps to support P.
   • The need to care plan to support decision making and enable people as much as possible, with the same attention that we care plan for self care / medical needs, is often overlooked. “Lack of capacity” is too often treated as permanent and generic, rather than decision specific, sometimes without thought to supporting improvement to greater exercise of capacity.
   • The principle that consideration must be given to whether there is a “less restrictive option” that might meet P's best interests is often misinterpreted as making it mandatory that the “least restrictive option” is taken.

15. The quality of documented capacity assessments can be poor – often not time / decision specific, or carried out by someone who doesn’t understand the information relevant to the decision – or done once on admission and not reviewed.

16. It is difficult to audit the use of MCA effectively, as many decisions are made informally, outside institutional care settings, and even inside care homes and hospitals data collected (even on DOLS, for example) tends to be quantitative rather than qualitative, making real benchmarking challenging.

17. MCA does now provide a framework for discussion of capacity and best interests issues, which can support reflection and learning lessons when things go wrong, and also makes it more legitimate for different opinions to be held, taking into account factors on either side on what are essentially binary decisions – capacity or not – best interests or not – that are in reality mostly not black and white, and where there is a reasonable scope for disagreement and resolution.

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Decision making

18. There is often uncertainty over the weight to be given to P’s own wishes – for example not understanding that these need to be taken into account in any evaluation of best interests.

19. The MCA, it is felt, has encouraged professionals across health and social care to take a much wider, more rounded view of best interests, than may previously have been the case, though an undue focus on narrow medical issues in such cases can still be found.

20. MCA now encourages a decision maker to consult more widely with those engaged in caring for P or interested in his welfare (where previously they may have just gone to the “next of kin” only) but in reality there is still significant deference to family and there is confusion over the role of those consulted, which ought to focus in particular on helping the decision maker take into account P’s own wishes, values and beliefs – see esp MCA s4(6) / (7). Sometimes the “next of kin” have unrealistic and inappropriate expectations that they are the decision makers, and this lies at the root of many disputes, but this misplaced expectation can also be burdensome for them if they feel expected to make a decision.

21. The MCA does not in our view do enough to make it absolutely clear that capacity to make a decision means the choice among actual available options, and so a lack of capacity does not mean that a “best interests” argument can be used to demand options / resources that would not otherwise have been offered. Though case law has recently helped to clarify this, we often find arguments put on behalf of a patient of their family that a lack of capacity should effectively confer advantage to the patient in resource allocation decisions that ought to be challenged, if at all, only by way of Judicial Review, not in the Court of Protection.

22. There is often confusion over the function of LPAs / deputies, ie the different kinds, need for registration with OPG etc, and the restrictions that remain on their decision making.

23. Effective use of Advance Decisions is a comparative rarity in our experience, and for the intention of these provisions to be fulfilled, there may need to be more support for people to help make advance decisions and to ensure that they are valid and applied.

24. The role of IMCA is valuable and “one of the best things about the MCA” in our clients’ views, though there needs to be clear boundaries and clarity of role.
• They are not used often enough in safeguarding, and usage levels varies across local authorities.
• Rates of IMCA referral for serious medical treatment decision referrals feel lower than would be expected, but audit and benchmarking stats are difficult.
• There is inconsistency in their involvement – eg a P is much more likely to get an IMCA for a care plan review if there had been one involved in a change of accommodation decision as well.

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• There is a concern that the need for advocacy for P can be masked where there is "consensus", if IMCAs are only involved in cases of dispute. What about people who do have family with clear views, which may not be P’s own views?
• There should be a review of IMCA training, which has often been focussed on the MCA rather than the IMCA role specifically, and for which there is little quality assurance or accountability. Theirs is a key role at a pivotal time in the lives of very vulnerable people, and it could be professionalized, perhaps with a mandatory professional qualification, or a quality performance mark?
• There is a lack of benchmarking across various advocacy provider organisations.

DoLS

25. We should not lose sight of the fact that Stephen Neary would not have been reunited with his father if not for the (eventual) use of the DoLS system, and the challenge this allowed. Identification of an actual or potential deprivation of liberty now triggers a process of scrutiny which includes independent reviews, representatives, a plan, and often an improvement of their quality of life. However, the consensus is that this is the least successful aspect of the MCA, with the drafting complex and the system unwieldy.

26. Effective benchmarking and sharing of experience and expertise are hindered by the same issues identified above – lack of national guidance / resource, and where data is collected it is largely quantitative rather than qualitative.

27. Training is not quality assured – even the mandatory statutory refresher training.

28. There remains an inherent reluctance among providers of health and social care to identify a DOL, perhaps as a result of the negative connotations of such a pejorative phrase, in contrast to, for example, “protective care”. In many cases a DOL is not identified in practice unless there is active and vocal objection by the person in question, which may operate inappropriately to deny the procedural safeguards to some of those who need them most.

29. There is real concern that this most fundamental question – what is a deprivation of liberty? – is opaque, and guidance from the courts can seem inconsistent.

30. To the extent that guidance / case law has been forthcoming, it has not always been helpful. Elements of the case law have been of concern, as apparently supporting or introducing factors which could be confusing, misleading, or construed as arbitrary or discriminatory. We would hope that the forthcoming Supreme Court judgment in Cheshire will bring some clarity.

31. There is also an issue that the Safeguards, as they currently stand, provide procedural protection only in care homes and hospitals, while some of the most vulnerable people may be in the community or in supported living. We would
support the extension of DOLS, or an equivalent system, to cover those other groups.

32. The current system makes enormous practical demands on those involved, especially for urgent applications, or renewals too late before the expiry of the previous standard authorisation, when it’s very difficult to get everything done in time. The supervisory body needs to scrutinise the assessments, but there isn’t much time for them to do this.

33. The enormous and alarming regional variation in the use of DOLS appears to be unjustifiable and needs investigation.

Court of Protection and the Office of the Public Guardian

34. Some clients have expressed a frustration at the OPG’s inability in to record a flagged concern on a system that would then be picked up again later if there were further issues. The only way to raise concerns seems to be an application to Court.

35. The introduction of health and welfare LPAs is seen as a good idea and empowering, but there is often misunderstanding about LPAs generally – that they are not operational unless P lacks capacity for the decision which is within the LPA’s scope, and they are not a blanket authority to act in any way the attorney sees fit on any decision.

36. Costs of a Court of Protection application are sometimes seen by clients as prohibitive, and it is felt to be an unwieldy process. There is a view among our clients, especially those who regularly work with the Mental Health Act, that an arrangement more akin to the Mental Health tribunal system would be better.

37. LSC funding is not sufficiently available, and it feels arbitrary that DOLS appeals are LSC funded without means testing, while welfare disputes are not, when substantially similar issues may be involved.

38. But there is also nowhere near enough use of informal dispute resolution services for MCA / COP matters. This may not be straightforward, and there will be a challenge over the actual and perceived independence of any decision making mechanism if it is funded and delivered by the public body with which there is a dispute, or whether a patient or family could or should be expected to meet some of the costs, or how any such ADR could be binding, while meeting ECHR Article 6 rights. Nonetheless, we agree that it would be positive to see much more resource and attention given to alternative ways to resolve disputes, with the Court used as it should be as a last resort.

39. Having said that, there is still sometimes a lack of awareness over the kinds of cases that must go to Court – seen recently in a non therapeutic sterilisation case where a clinician was in the first instance happy to proceed on the basis of the female patient’s family’s wishes (A Local Authority v K, 2013). In other cases, there is uncertainty over the level of dispute that should trigger an application to Court.

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40. We welcome the more open reporting of Court of Protection cases, as important for the transparency of justice, and vital to counter some of the disparaging perceptions and media coverage of the Court as some secret tribunal.

41. In the relatively early stages of development of a jurisdiction, it is unavoidable that case law can appear contradictory. High profile cases which have been critical of public bodies and others have helped to focus attention on the relevant issues, but there is a long way to go. Overall not enough cases are taken to Court.

Regulation

42. There is frustration at the inconsistency between the annual returns on MCA / DOLS and the data that the CQC want to collect. It would be sensible for this to be co-ordinated, and for all the relevant information to be collected once and once only.

43. We welcome the imminent appointment of a dedicated senior role within the CQC to lead on MCA and DOLS issues nationally, which we expect to have a very positive effect.

44. We would caution against fragmentation or duplication of regulation in this area.

Other Legislation

45. One of the most frequent issues we are asked to deal with is the relationship between the MCA and MHA. The drafting of Schedules A1 and 1A in particular does not help, and as mentioned above in our view the reference in the title of the MCA to “mental” capacity is unnecessary and prone to cause confusion with the MHA, even among health and social care professionals.

46. There is an inconsistency in approach between the principles of the MCA - that the person best placed to assess capacity is the practitioner helping P to make a particular decision, ie it could be a Discharge Nurse, OT, or a social worker – and the Court of Protection form 3 to certify a lack of capacity to start proceedings that must presumptively be completed by a doctor, psychologist or psychiatrist.

47. There are still examples of patients who are detained under the Mental Health Act being treated as if they therefore lack capacity for all decisions, and of patients whose decisions about physical health needs, where the compulsory treatment powers of the MHA cannot be applied, are not properly considered under the MCA framework.

48. There is also a significant challenge in the management of patients for their physical healthcare needs in acute hospital settings where they are also detained under the MHA but the acute Trust may not have readily available the experience or the mechanisms in place to deal with the due process under the MHA to ensure that the patient’s rights are properly protected.
In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
I am a solicitor working for a large local authority in England and I advise adult services on all aspects of adult social care and mental health law. The MCA 2005 impacts on about 90% of the work I do one way or another. I have been in this role for seven years since September 2006. On a personal level I have also been involved (on the periphery) when my aunt who was assessed as lacking capacity to decide where she should live was discharged from hospital into residential care rather than returning home. My mother has also recently, having obtained her own independent legal advice, appointed Health and Welfare and Finance and Property LPAs and made an Advance Decision. My response to the call for evidence from the public is personal arising out of my professional and personal experience.

MENTAL CAPACITY ACT 2005 – AIMS AND PRINCIPLES

Save for Schedule 1A (DOLS provisions) the MCA 2005 is a well drafted act which sets out a clear legal framework within which decisions and/or actions can be made or taken on behalf of those who lack capacity to make those decisions or take those actions themselves. If applied appropriately it is a tool for real potential empowerment for some of the most vulnerable people in our society. In my view the MCA 2005 has achieved its aims in respect of the decision making process to be used for those who lack capacity to make decisions is clear and unambiguous. It has been less successful in achieving its aim of encouraging support to be given to P to make his or her own decisions. If it was a statutory duty for an LA to appoint an IMCA for P as soon as a P is assessed as lacking capacity to make a decision, particularly major decisions such as moving home or care and treatment etc then I believe this aim could be achieved too.

The Act applies to those who are 16 years and over but I am not sure that the aims and principles of the act have been applied to those that fall within the 16yr – 18yr age group who lack capacity to make decisions or who have a cognitive impairment that compromises decision making. I do not see the principles of the act either in the best interest decisions making process or in supporting 16+ P to making his or her own decisions. If it was a statutory duty for an IMCA to be appointed for P at the age of 16 as his/her advocate that would be seen as a first step of autonomy for P while the parents still held authority for finances, medical treatment, information sharing etc.

DEPRIVATION OF LIBERTY SAFEGUARDS

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
The DOLS provisions as set out in Schedule 1A fail miserably in their aim to protect a person who lacks capacity to decide where they should live or on their care or treatment. These safeguards should be extended to supported living accommodation and in my view to Shared Lives (cf foster care) accommodation.

By calling them ‘deprivation of liberty safeguards’ it has in my experience limited the application of Schedule 1A to literally deprivation of liberty in respect of confinement to a building or space, and/or various degrees of restraint, but does not in my experience extend to consideration of ‘treatment’ particularly medication that might be routine but for which P lacks the capacity to consent to. It was precisely this lacuna that *Bournewood* exposed. In my experience people who lack capacity to consent to their care and treatment including medication but who are compliant are rarely considered potential ‘candidates’ for review under Schedule 1A.

Schedule 1A is badly worded, there is no definition of ‘deprivation of liberty’ and jurisprudence has relied on Article 5 and Strasbourg and this has left us with the pending Supreme Court cases of *P and Q* and *Cheshire West*. If one of the aims of the MCA was to protect the autonomy of P it is difficult to see how the notion of ‘a comparitor’ sits with that. I am also particularly concerned about the numbers of people who are in psychiatric wards or hospitals as ‘informal patients’ who do not have the capacity to consent either to being there or to their treatment. If P tried to leave s/he would be prevented from doing so by cajoling and stronger means and if P becomes challenging when receiving medication or just generally would be restrained and/or forcibly sedated. This is assault.

The safeguarding provisions are woeful:

a) the appointment of an IMCA for P is unclear (cf IMHA under the MHA 2007) and the role of an IMCA for P is also unclear. I suggest that there should be a statutory duty for the Supervisory Body to appoint an IMCA for P as soon as a DOL is being considered. An IMCA should have the right of ‘appeal’ of a DOL. Their role should be as similar as possible to an IMHA.

b) The choice of RPR is a BIA’s recommendation but the choice of the Supervisory Body. I suggest that there should be a statutory list as per s26 MHA 1983 from which an RPR should be appointed. That list should include an LPA (health and welfare). As well as the power to ‘appeal’ the RPR should have a power of discharge (cf powers of nearest relative under the MHA 1983).

c) There is no clear process of challenging a potential deprivation of liberty or care and treatment without consent (Judicial Review or CoP) unless a DOLS Authorisation is in place. Even then an appeal to the Supervisory Body (rather than a court/tribunal) is almost certainly in breach of Article 5(4) and if appeal is to the Court of Protection it is slow cumbersome and expensive. I suggest that the challenge to a DOLS Authorisation should be through a Tribunal (as per First Tier MH Tribunal) which could be convened quickly and sit within the care home or hospital setting. There should be a presumption that P would attend and have legal representation, that the RPR would attend plus professionals others with an interest.

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d) I have seen the written submission dated 25 August 2013 sent in by Victoria Butler-Cole from a group of practitioners and agree with all their comments about the deprivation of liberty safeguards.

ROLE OF THE IMCA

The MCA 2005 in my view upholds the principle of the autonomy of P whether or not P has the mental capacity to make a decision or not, and that every effort should be made to enable P to retain his or her autonomy and be part of any decision making process. However, to have the IMCA as an appointment of last resort (no family/friend to speak for P) seems to me to contradict this principle. In my view an IMCA should be appointed to P whenever major decisions are to be made, whether contentious or not, such as a move from home to residential care, moving schools, setting up/change of/reviewing care and treatment, assessments, medical/dental appointments etc. An IMCA’s role would be to both support P in making his/her own decisions, and also where P simply cannot, to ensure that P’s voice – his/her wishes are clearly given, recorded and considered.

Clearly appointing an IMCA to every P who lacked capacity or whose capacity was compromised would require a large increase in the financial resources and the recruitment of a large number IMCAs. There is a wealth of talent in our active but retired population and in our youth to gain experience in this area. Carers UK provide excellent training for advocates.

LPAs

Even though the forms have recently been simplified it is still a complex and expensive process. At a small private practice in North Wales the drafting and registration of two LPAs (health and welfare and finance and property) and an Advanced Decision for my mother cost £1,000+. Even as a lawyer with experience of working with the MCA 2005 I would still seek advice. At work we are only this year beginning to see the first LPAs coming through but they are few and far between and the old EPAs still outnumber them by a significant margin.

PROFESSIONALS

I agree with the oral evidence given and the written submissions that I have seen that social workers (and at my LA training is excellent for both social workers and BIAs) have a good understanding of the MCA 2005 and dedicated efforts are made to apply its principles and aims. However my experience of the application of the MCA 2005 in health settings, whether private or NHS hospitals, whether for mental or physical medical treatment, particularly when that care or treatment may be considered ‘routine’ the understanding and application of the MCA 2005 is lamentable.

LEGAL AID

P who lacks capacity to make a decision that the court is asked to make should be entitled to non means tested legal aid whatever the issue. Without it P is likely to go...
unrepresented in proceedings other than DOLS challenges. Disputes about whether or not P should go into or remain in residential care or with regard to his care or treatment are major life changing decisions and P should be part of that process with full legal representation. That P may not be represented and have no voice whatsoever in this process because s/he lacks the means to pay the Official Solicitor or any other lawyer to represent him/her is iniquitous.

I am aware of complex Court of Protection proceedings where the LA has been the only party with legal representation. This is simply not fair to anyone. The LA is landed with all the litigation ‘tasks’ and often has to pay the full costs of any experts; litigants in person may not be English speakers, almost certainly will never have entered a court before, cannot provide evidence in the right form or cannot or do not comply with court orders and directions causing delay and very real difficulties in perhaps securing an early settlement of the dispute.

Legal Aid should also be available for mediation for P and all private parties in a dispute. Whatever the outcome of a dispute P, the LA social workers and P’s family are almost certainly going to have to work together when it is resolved and/or the proceedings are over and the less adversarial this process is the better for P.

Just for the record however, apart from the DOLS provisions which are inadequate I think it is a great piece of legislation.

31 August 2013
In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.


Background to this response

1. This document was produced following a meeting arranged by Victoria Butler-Cole and Alex Ruck Keene of 39 Essex Street between a group of solicitors and barristers working in the Court of Protection which took place at 39 Essex St on 2 August 2013.

2. The views contained in this document are an amalgamation of the views of the group in response to the questions posed by the Select Committee. It focuses primarily on health and welfare matters. It does not purport to represent the views of particular firms or chambers. The document focuses on identifying particular areas of concern and ideas for improvement, based on the participants’ experience of cases in the Court of Protection and cases under the MHA 1983.

3. The practitioners who took part in the meeting are:

   Neil Allen   Barrister, 39 Essex St
   Andrew Bowmer  Solicitor, Steel and Shamash
   Victoria Butler-Cole  Barrister, 39 Essex St (convenor)
   Julie Cornes   Solicitor, Maxwell Gillott
   Charlotte Haworth Hird Solicitor, Bindmans
   Laura Hobey-Hamsher Solicitor, Fisher Meredith
   Laura Jolley   Solicitor, Mills and Reeve
   John McKendrick  Barrister, Outer Temple Chambers
   Alex Ruck Keene   Barrister, 39 Essex St (convenor)
   Polly Sweeney   Solicitor, Irwin Mitchell
   Rachel Turner  Solicitor, Miles and Partners

4. In addition, Paula Scully, solicitor at Derbyshire County Council, provided her views in writing.

Overview and context

5. We see the following areas of the Act as requiring amendment:

   a. Section 44;
   b. Schedule 1A (for clarity);
   c. Regulations about Schedule 3 and confirmation as to whether it is in force.

6. S.44 MCA 2005 (the offence of wilful neglect of a person without capacity) has been the subject of heavy judicial criticism in R v Dunn [2010] EWCA Crim 2935,
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7. Schedule 1A was recently described by Baker J as “one of the more difficult provisions in this complex legislation,” in An NHS Trust v Dr A [2013] EWHC 2442 (COP) a case in which he identified another difficulty in the drafting of the MCA 2005 that opens a gap every bit as troublesome as that identified in the Bournewood case itself. In brief, the case concerned a person subject to detention under the Mental Health Act 1983 who was to be treated in a way outwith the treatment provided under that Act for his mental disorder, if that treatment involves a deprivation of liberty. Such a person would be ineligible to be deprived of their liberty (whether by way of a standard authorisation or by way of a court order) because of the operation of Schedule 1A. Further, if the treatment could not properly be said to be treatment falling within the compulsory provisions of s.63 MHA 1983, then the MHA 1983 would not afford a route to authorise the administration of such treatment and any ancillary deprivation of liberty. As Baker J identified:

‘To take a stark example: if someone detained under section 3 is suffering from gangrene so as to require an amputation in his best interests and objects to that operation, so that it could only be carried by depriving him of his liberty, that process could not prima facie be carried out either under the MHA or under the MCA. This difficulty potentially opens a gap every bit as troublesome as that identified in the Bournewood case itself.’ (para 67)

In the case before him, it was clear that (a) the adult lacked the capacity to decide whether to consent to forcible feeding; (b) that such forcible feeding would involve a deprivation of their liberty; (c) that it was in the adult’s best interests; but that (d) the forcible feeding could not be said to be medical treatment for the mental disorder from which he suffered so as to fall within the provisions of MCA s63. After an exhaustive analysis of the statutory provisions and the authorities, Baker J held that he could not read into the prohibition in MCA 2005 s16A(1) against welfare orders being made depriving ineligible adults of their liberty the words ‘save where such provision is necessary to uphold the person’s right to life under Article 2 of the European Convention on Human Rights,’ but that he could authorise forcible feeding and the ancillary deprivation of liberty by way of the exercise of the inherent jurisdiction. As he noted, it was ‘alarming’ that the legal position on this fundamental issue was far from straightforward, and the fact that he had to resort to the inherent jurisdiction to authorise so plainly necessary a state of affairs is equally concerning.

8. As regards Schedule 3, it is not clear on its face whether the entirety of Schedule 3 is in force (this question is currently before the President of the Family Division, Sir James Munby, and it is likely that a judgment on this issue will be handed down in the early autumn; it is, however, frankly extraordinary that the position is not clear over five years after the Act came into force, and that judicial time and public money has had to be spent in determining the issue).

Regulations also need to be made:

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(i) Under paragraph 15, to clarify what formal requirements must be complied with in order for a ‘foreign’ power of attorney to be effective in England and Wales. This is particularly important given the current uncertainty regarding the position of Scottish powers of attorney in England (Scotland being a foreign country for these purposes). The Committee is respectfully invited to have regard to the information provided on the Scottish OPG’s website (http://www.publicguardian-scotland.gov.uk/faqs/index.asp)

Q. Can a Scottish Power of Attorney (PoA) be used in England?

A. A Scottish PoA can be used in England if an Organisation (e.g. a bank) accepts its authority but if they do not there are difficulties. What the Organisation may require is an endorsement of the Scottish PoA from the English authorities [Public Guardian or Court of Protection] but the English legislation does not appear to permit these authorities to offer this endorsement. If a Scottish PoA can’t be used without an endorsement but one cannot get such an endorsement the Scottish PoA becomes a worthless document. It is recognised that this is an unacceptable position and perhaps not what was intended. The matter rests with England to agree and make any changes that are required.

(i) If you are now based in England and are still capable you may wish to consider doing an English PoA. If capacity has been lost someone will need to apply to the Court of Protection for deputyship (equivalent of Scottish guardianship).

(ii) If you need more information about the English system or how best to proceed in England please contact the Office of the Public Guardian for England & Wales, telephone: 0300 456 0300 e-mail: customerservices@publicguardian.gsi.co.uk

(ii) Under paragraph 32 (and/or the Court of Protection Rules 2007 amended) so as to set out, for instance, the procedural steps required in order for a declaration to be obtained that a foreign protective measure should be recognised and declared enforceable in England and Wales. There are very detailed provisions contained in Part 31 of the Family Procedure Rules 2010 for the obtaining of similar declarations in respect of measures taken in respect of children under Council Regulation 2201/2003, and similar provisions should be enacted in respect of Schedule 3. This is particularly important given that the purpose of Part 4 of Schedule 3 is to enable ‘summary and mandatory’ effect to be given to protective measures taken in respect of incapacitated adults in foreign jurisdictions – for instance, by way of bringing about their speedy return to the county from which they were abducted (see Re MN (Recognition and Enforcement of Foreign Protective Measures) [2010] EWHC 1926 (Fam) per Hedley J).

Implementation

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
9. Our general shared impression is that health professionals have a much weaker knowledge and awareness of the MCA 2005. Their capacity assessments can be less thorough and less compliant with the MCA and the Code of Practice, including on basic issues such as the need for an assessment of capacity to be decision-specific. We find the quality of capacity assessments to be of variable quality and very poor in some many sectors, including even some experts instructed in the Court of Protection, and Court Visitors.

10. We have the impression that where decisions a person makes are contentious, there is often a swift conclusion that the person lacks capacity, and substituted decisions are made for them. There is a lack of rigorous analysis of whether a decision is unwise, as opposed to incapacitous, and no real commitment to assisting a person to make a capacitous decision. The assessment of capacity is too often treated as a one-off ‘test’, rather than a process in which the role of the assessor (and others) is to help the person to make his own decision.

11. Our experience is that the best capacity assessments are by people who know P, and who have experience and training in communicating with people with disabilities, and who see their task as assisting P to make a decision, not testing P’s knowledge. In general, capacity assessments which are conducted with the aid of a template or written guidance tend to be better, as practitioners follow all the steps set out in the Code of Practice. In the East Midlands, steps are being taken to trial revised DOLS capacity assessment forms which incorporate the COP3 form to ensure that all the steps in assessing capacity are completed.

12. The Code of Practice would benefit from being updated about the assessment of capacity, to identify potentially relevant information to certain types of decision, and to set out the guidance given by the courts. There does not seem to be any formal route for the court’s guidance on capacity from its caselaw to be fed back to practitioners on a regular basis.

13. We also think that much greater clarity is required for statutory bodies, in particular local authorities, about their powers to enter premises and remove people who are at risk of harm, and the circumstances in which the prior approval of the Court of Protection, or the High Court under the inherent jurisdiction, is required. The Code of Practice could usefully include case studies to assist local authorities, dealing with problems such as severe self-neglect.

Decision-making

14. There is a lack of focus on the idea of supported decision-making. The Code of Practice checklist is often not applied, and the assessment of capacity is seen as a test of whether P can justify his disagreement with the advice of professionals rather than a way of trying to assist P to understand the relevant information and form a decision.

15. Once proceedings are in court, there is comparatively little focus on capacity. Often, declarations about P’s lack of capacity are granted without the evidence
In order to protect individuals the Committee has chosen in some cases to remove identifying information from
the submissions.

16. We note that question 10 refers to the idea of ‘general authority’ – there is no such concept in the MCA 2005, and this reflects a common misconception that the MCA gives you the power to do things, when in fact provides a common law defence to liability. One example we have seen is a decision to move an elderly man to a care home against his wishes where a GP said words to the effect that ‘Now P lacks capacity, we can move him’ whereas previously P had made a series of apparently unwise but capacitous decisions to live at home.

17. There is a lack of clarity as to whether or not there is a hierarchy of decision makers. Social work professionals can assume that they are the decision makers when there is a dispute. Amending the Code of Practice to clarify that this is not the case would be helpful. There is also little awareness amongst professionals as to the practical impact of a relative becoming a health and welfare attorney under an LPA or a health and welfare deputy. Professionals can have difficulty in accepting that this places that person at the top of the hierarchy and that they need to ask COP to adjudicate on this issue.

18. We know of some examples of advance decisions to refuse medical treatment not being respected, but the court’s involvement not being sought. We cannot give a general picture of the extent to which this is happening, but we suspect that it could be fairly frequent, since in a life and death situation, a health professional will (understandably) be very anxious about complying with a refusal of life-sustaining treatment, and there are numerous ways in which the validity and applicability of an ADRT can be questioned.

19. We have the impression that the MCA 2005 has probably led to more explicit ‘best interests’ decisions being taken, with more meetings and documentation of decisions. We suspect that where family members agree with the statutory body, they are consulted, but where they do not, they are marginalised. Local authorities often decide not to consult family members when safeguarding alerts have been raised, but the quality (and speed) of their safeguarding investigations can be very poor, which means that valid views are not taken into account. We know of numerous cases in which decisions made by public bodies subsequently turn out on proper consideration to have been flawed, often because the views of relatives were not taken into account properly, or were discounted due to unsubstantiated concerns about their conduct.

20. We have the impression that local authorities can be confused about whether they are making public law decisions about service provision, or best interests decisions, and how the two types of decision are related.

21. We feel that IMCAs can be excellent, but that there is much inconsistency across the country. There should be more IMCAs, and they should be independently funded. They should have clearer guidance about their role and their potential role as litigation friend in court proceedings.
Deprivation of liberty safeguards

22. The concept behind DOLS, of requiring independent assessments of capacity and best interests, with mechanisms for review and challenge, is a good one. It should be applied to all significant decisions affecting potentially incapacitated adults, not just those where deprivation of liberty is involved (not least since the definition of deprivation of liberty is so open to interpretation). Guidance would then be required about when the MCA safeguards would be needed. One possibility would be that they were required in any case where P objected to the proposed arrangements, or where a potential deprivation of liberty was involved.

23. The view of the group was that the DOLS safeguards in their current form are not working. Specifically:

a) The capacity assessments that are conducted are often of poor quality and fail to reflect the requirements of the MCA 2005 or the caselaw of the Court of Protection. There does not seem to be any specific training requirement for capacity assessors.

b) It is very often the case that DOLS authorisations are put in place when P is already in the placement s/he objects to. We have seen many, many cases in which P is discharged from hospital to a care home against P’s wishes, but no authorisations are applied for at that stage, nor is the Court’s involvement sought. Once P is in a care home, it is exceptionally difficult to persuade the Court that s/he should return home, no matter how vociferously P objects to his/her placement – the status quo usually prevails, and/or the statutory bodies simply refuse to fund care at home for P which means that there is no option of a return home. There seem to be no penalties for statutory bodies who fail to comply with the Code of Practice or the court’s guidance about authorising a deprivation of liberty in advance.

c) The DOLS safeguards should be extended to supported living placements, childrens’ homes and residential schools.

d) Further guidance is required about whether DOLS authorisations can authorise the use of physical restraint, and if they can, additional independent oversight and review should be required. The existence of a DOLS authorisation at present is sometimes relied on as justifying all treatment of P, including physical restraint, without adequate exploration of whether that restraint is required, or how it is being administered.

e) There do not seem to be sufficient internal reviews conducted, and nor are IMCAs involved in reviews. There is inadequate information given to Relevant Person’s Representatives or family members about their rights to challenge a DOLS authorisation. For example, they are not generally given a list of solicitors they could contact, or full details

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of their rights as a Nearest Relative would be under the MHA 1983. It is not clear whether the Code of Practice is compliant with Article 5(4) ECHR as it suggests that court review of a DOLS authorisation is optional.

f) There is confusion about the role of IMCAs. They should be focusing on promoting P’s views and wishes, not acting as a pseudo-independent best interests assessor. IMCAs can be reluctant to pursue P’s wishes when the IMCA is funded by the same statutory body that is funding P’s care, and when the merits of P’s objection seem relatively low.

g) There is also apparently a lack of clarity about when IMCAs should be appointed – the statutory provisions are unnecessarily complex.

h) There are problems with appointing RPRs. Often, family members are not appointed if they are already in conflict with the statutory body. On other occasions, a family member will be appointed as RPR who agrees with the DOL, and therefore P’s right to challenge it is not pursued. Where a family member is the RPR, we think that a s.39D IMCA should always be appointed to avoid this problem.

i) Once in the court arena, if interim declarations are made, not only is non-means tested public funding withdrawn, but the entitlement to an RPR may also be lost. There needs to be some clear guidance about the interplay between DOLS authorisations and court proceedings to ensure that P is not prejudiced.

j) There is a lack of adequate remedies for technical breaches of the DOLS safeguards, which makes it difficult to promote best practice.

24. There needs to be clarity in the Code of Practice as to whether a DOLS authorisation includes a power to convey P to the place of residence, and the role and powers of the police in conveying P.

The Court of Protection and the Office of the Public Guardian

25. The Court of Protection staff in London are well trained and helpful. The written guidance on applying to the Court of Protection is much less helpful and could usefully be rewritten. In contrast, the guidance on applying to register LPAs is much more user-friendly. The Court of Protection forms should be streamlined and the recommendations of the Rules Committee made in 2010 implemented swiftly. The recommendations of the Rules Review Committee were accepted in full by the then President, Sir Nicholas Wall:

11 An attempt at providing some additional guidance for litigants in person has previously been drafted by one member of the group and is available at www.courtguides.wordpress.com.

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http://www.judiciary.gov.uk/media/media-releases/2010/news-release-2210. They contained detailed recommendations both about the forms, and also, more widely, about other aspects of the Court of Protection Rules and accompanying Practice Directions that reflected the experience of the first years of the operation of the MCA 2005. With one exception (that of the introduction of Rule 7A and Practice Direction 3A, allowing court officers to exercise limited case management powers), the recommendations have yet to be given effect.

26. There is a lack of consistency between London and regional courts, and frequent problems with documents being lost or unavailable, and orders not being sealed promptly. While these can be dealt with (at time and expense) by solicitors, they are very difficult for litigants in person to manage.

27. The court process can be very long winded. This is due in part to appropriate standard orders not being made at the outset of applications; delay in the Official Solicitor accepting an invitation to act as litigation friend; and a lack of incentives for parties to agree and stick to court timetables.

28. There is marked variation in the willingness of judges to meet P and allow P to give evidence, or put across his/her views in whatever way is suitable. Guidance for the courts on hearing from P should be provided, for example by way of a further Practice Direction. We have considerable doubts that the current system which does not presume that judges should have ‘personal contact’ before making decisions about their capacity or best interests is compatible with the ECHR in light of the decisions of the European Court of Human Rights in Shtukaturov v Russia (2012) 54 E.H.R.R. 27 and ECtHr in X and Y v Croatia Application No. 5193/90, decision of 3.11.11, the Court in the latter case holding that judges adopting decisions with serious consequences for a person’s private life, such as those entailed by divesting someone of legal capacity, should in principle also have personal contact with those persons’ (para 84).

29. Having district judges dealing with cases has made the court more accessible. This could be extended by amending the statutory provisions so as to allow for the appointment of deputy district judges. There are some courts in which district judges have had no training in the MCA 2005 – this should not be acceptable. Specialist training is essential as the jurisdiction is not the same as the Family courts.

30. More emphasis could be given to mediation, and the Legal Aid Agency should be more willing to fund representation at mediation. It would be helpful if an approved register of mediators from a range of disciplines could be established.

31. There is confusion about what counts as ‘serious medical treatment’ and when health professionals need to go to court to obtain declarations. One example is a case in which an autistic young adult had all his teeth permanently removed to stop him self-harming, without the Court’s involvement.

32. There is insufficient guidance for IMCAs about acting as litigation friend in proceedings - what their role would entail, whether they are at risk of a costs
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33. There is a lack of awareness about LPAs and their effect amongst professionals. We have examples of cases where a welfare LPA exists, but the statutory body is not respecting the decisions of the donee, and is not applying to the Court of Protection to have the LPA revoked. This ride roughshod over the purpose of the LPA provisions in the MCA 2005 – LPAs cannot be overridden at will, the court’s intervention is required.

34. The cost of applying to the Court of Protection is offputting. We have examples of cases where people have decided not to apply to the Court for a decision because of the costs. In cases that have both welfare and financial elements there is a lack of clarity about how costs will be apportioned – this needs to be resolved by way of a Practice Direction.

35. The Legal Aid Agency funding for Court of Protection cases is not consistent and restricts funding inappropriately. Detailed submissions on this point will no doubt be made by others. We note in particular that the LAA’s tendency to withdraw non-means-tested public funding in DOLS challenges once the court has made any interim declarations about P’s best interests means that DOLS challenges have to be withdrawn due to funding difficulties. We know of cases in which this has happened, which has meant that P has not had the independent review of his/her deprivation of liberty required by Article 5(4) ECHR. We have not been able to obtain a copy of the LAA policy on funding for DOLS challenges under s21A MCA 2005, if one exists.

36. Further, since changes to the capital passport in April 2013, it has become much harder and more time consuming to investigate P’s entitlement to legal aid. This difficulty is compounded if the litigation friend is an advocate or family member rather than the Official Solicitor.

37. Lastly, we are all very concerned that the funding does not expressly cover cases in which P’s right to respect for private life under Article 8 is engaged, but only P’s right to respect for family life under Article 8. This means that, for example, if P is being moved from one community placement to another and objects, he may not be granted public funding, whereas he would do if he was moving from a family placement to a community placement. This limitation appears to be based on a false view of incapacitated adults as somehow equivalent to children.
Regulation

38. There should be a clearer system for reviewing and authorising the deprivation of liberty of a person in a supported living placement (whether or not the DOLS system is extended to cover supported living).

39. There should be guidance from the CQC for service providers and commissioners about what steps have to be taken when premises have a change in registration and residents are moved, with particular reference to the MCA 2005. Guidance should also be provided about steps to be taken when premises are closed or contracts terminated due to concerns about the quality of care provided.

40. The CQC should provide public guidance about the circumstances in which specific policies are required, as in the case of GU [2012] EWHC 3531 (COP).

41. The CQC and/or DoH should redraft the DOLS forms to make them simpler and less voluminous.

42. Consideration should be given to training and guidance for OFSTED about identifying unlawful deprivations of liberty in residential schools and childrens’ homes.

Other legislation

43. In addition to the troubling further lacuna identified in the Dr A case discussed at paragraph 7 above, there were various issues identified about the inter-relationship between the MHA 1983 and the MCA 2005:

   a. How do the two Acts work in relation to decisions about contact between an incapacitated person and others? Which has priority? What should happen in the event of disagreement between the Court of Protection and the responsible clinician under the MHA 1983?

   b. Is there sufficient knowledge about the application of the MCA in respect of informal psychiatric patients? Are proper capacity assessments being conducted in relation to informal patients?

   c. Is there any proper mechanism for dealing with standoffs between a DOLS best interests assessor (who thinks that P is ineligible to be deprived of his liberty under the MCA 2005 Schedule 1A because P falls within the scope of the MHA 1983), and an Approved Mental Health Practitioner (who considers that P does not meet the criteria for an application for detention under the MHA 1983)?

   d. There appears to be a lack of clarity about the relationship between guardianship under the MHA 1983 and deprivation of liberty.

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e. There seems to be a serious lack of training of hospital inpatient staff about the MCA 2005, and the need to authorise deprivations of liberty through the DOLS procedure.

f. There can be a lack of awareness that when patients are discharged from detention under the MHA 1983 and are provided with aftercare under s.117 MHA 1938, the MCA 2005 may still apply to them and require consideration of their best interests.

International context

44. The group had the impression that there are fewer applications to the Court of Protection in Wales, and that solicitors in Wales are less familiar or experienced in the Court of Protection, but do not have any concrete evidence to support this impression.

25 August 2013
1. To what extent has the Mental Capacity Act 2005 (MCA) achieved its aims?
   • It has compelled decision-makers to justify decisions they make with an emphasis on the individual and their personal best interests
   • It encourages more open and transparent decision making between professionals
   • Family and friends are more easily considered

2. Which areas of the Act, if any, require amendment; and how?
   • The strict criteria of when an IMCA advocate can become involved inhibits earlier involvement as well as post decision involvement
   • The non-statutory nature of adult protection/safeguarding referrals and care reviews

3. At the core of the MCA are its principles and definitions of capacity and best interests. Are these appropriate?
   • Yes

4. To what extent have the five principles of the MCA been implemented in frontline practice? What evidence is available to assess this? Is there a satisfactory balance between enablement and protection?
   • There has been a greater appreciation and therefore application of the presumption of capacity.
   • There continues to be tension in relation to the right of individuals to be supported to make their own decisions.
   • Eccentric decisions are seen as eccentric decisions and are challenged by professionals more than what are regarded as normal decisions. The MCA however, enables a more confident and robust challenge in support of eccentric decisions. Eccentric decisions also involve an in depth knowledge and understanding of an individual which in many situations is lacking
   • There is an expectation that decisions are made in someone’s best interest and have to be explained. This helps
   • Least restrictive intervention rubs shoulders with what is the easiest and most cost effective.

Generally there continues to be tension between enablement and protection. Enablement would be best expressed if we had a cultural shift toward citizens being supported to make plans before they lose capacity. As with childcare, local authorities are vulnerable to media exposure which also encourages a risk-averse culture. Better safe than sorry. Likewise there are many examples of assertive and brave decisions.

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5. How effective was the Government’s implementation plan? What measures were taken to ensure that professionals and families of those who lack capacity know about and act in accordance with the provisions of the MCA? Has it led to sustainable change?

- It is noted that the expectation of raising awareness is with the provider of IMCAS when funding has been slashed for such a role
- There needs to be resources separately attached to awareness raising and should be in house

6. Is the Act widely known and understood by professionals required to implement it? How does this differ across different sectors, such as health, social care, banking and others?

- IMCAs spend lots of their time discussing and explaining the act to professionals.
- Understanding is patchy across sectors
- Stable teams promote greater knowledge and understanding of the act

7. Is the Act widely known and understood by those who are directly affected by it and by their non-professional carers? To what extent does the Act provide protection and reassurance for informal carers? Has the right balance between the protection of the carer and protection of the individual lacking capacity?

- The understanding of the provisions contained within the MCA, appear across all sectors not to have been absorbed into to practice when dealing with issues of capacity. This being indicated by the number of referrals received.

8. Has the Act ushered in the expected, or any, change in the culture of care?

- More transparent decision making
- Best interest incorporated into day to day and more complex decision making

9. Is there any evidence that the provisions of the MCA affect some groups disproportionately? If so, what data exists to compare representation across different socio-economic groups, Black and Minority Ethnic groups, and gender?

- There is anecdotal evidence to suggest that the more we know about someone, the more tailored decisions will be. The less we know, the more superficial decisions will be. This can have an impact on people grouped together by class or ethnicity and culture where the dominant culture is not as aware of the subtleties within that group

10. Are those directly affected by the Act being enabled and supported to make decisions for themselves to a greater or lesser extent than they would have been in the past? Does the means by which the decision is made – ‘general authority’, Lasting

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Power of Attorney, deputyship, Court of Protection – affect the quality of decision making?
• The process of checks and balances does make better overall decisions

11. What evidence is there that advance decisions to refuse treatment are being made and followed?
• The transfer of information and documentation related to advance decisions within the care home sector is not consistent and often lost

12. Has the MCA fostered appropriate involvement of carers and families in decision making?
• When decision makers determine family members as inappropriate to act on behalf of an individual, they (the individual) can become isolated from the best interest process.

13. Has the role of the Independent Mental Capacity Advocate (IMCA) succeeded in providing a voice for clients and an additional safeguard against abuse and exploitation for those who have no-one to speak on their behalf?
• Yes. The role provides a greater assurance that the client is at the heart of decision making
• It provides a constructive and critical voice in ensuring best interest is applied
• Without the role of the IMCA, there would be no means of checking professional decision-making.
• There is room for a greater role to be played by IMCA’s
• Decision makers are vulnerable to other overriding considerations, particularly in large settings such as hospitals where for example bed space is critical.

14. Has the level of referrals to IMCAs met expectations? What are the reasons for the regional variations in the number of referrals?
• Our IMCA service is working at capacity in two London Boroughs
• Too many reasons for variation including size of authority, knowledge of professionals around MCA, aging population hot spots

15. Are IMCAs adequately resourced and skilled to assist in supported or substituted decision making for people lacking capacity?
• Our IMCA’s are highly skilled and knowledgeable but resources negatively impact on quality and through-put. A good advocate needs time to advocate well. This may be across the professional board as there are less and less resources to adequately deal with the ever growing need to use the MCA
• It is getting harder to find qualified IMCA’s
• The squeeze on funding inevitably squeezes time for advocates to learn and develop and to have a career path. Highly skilled and knowledgeable advocate’s basic salaries are being squeezed and it is getting harder to attract suitably skilled IMCAS.

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The initial influxes of IMCAs were usually of professional graduate level (Doctors, Nurses, social workers, lawyers etc). Qualified IMCAS are leaving the profession.

Deprivation of Liberty Safeguards

16. Are the safeguards in the Deprivation of Liberty Safeguards (DoLS) adequate?
   • As the DOLS safeguards are subject to reinterpretation as a consequence of case law, there application can be variable

17. Are the processes for authorisation, review and challenge of DoLS sufficiently clear, accessible and timely?

The Court of Protection and the Office of the Public Guardian

18. Are the Court of Protection and the Office of the Public Guardian sufficiently understood and accessible to all? Are they operating effectively and successfully?
   • The delay in accessing the court of protection, resulting from the under resourcing of this provisions is impacting on best interests. The court of protection is perceived as being secretive and the process as not being open and transparent

19. What has been the impact of the introduction of Lasting Powers of Attorney (LPA), especially with regard to decision making on matters of personal care and welfare?

20. What concerns, if any, are there regarding the costs associated with registering an LPA, or with making an application to the Court of Protection?

21. Is legal aid available and sufficient? What impact will the recent and proposed reforms to legal aid have?
   • Reforms to should not really be described as reforms. They are cut backs to access to the justice system.
   • The cut backs will inevitably have a negative impact

Regulation

22. Is the role of the Care Quality Commission in inspecting on the MCA standards adequate and appropriate? Is there a case for additional powers?
   • The issue of establishing complex decisions on behalf of individuals who lack capacity in a care home setting requires to be closely monitored by the CQC and should be a core requirement in all inspections.

23. Should other regulatory bodies, such as health and social care professional regulators, be acting in this area?
   • There should be a corporate responsibility as with children in the care system (corporate parents)
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1.0 Introduction

1.1 The Cambridge Intellectual and Developmental Disabilities Research Group (CIDDRG) comprises clinical academics working in the local specialist services for people with learning (intellectual) disabilities and academic researchers who have engaged in grant-funded research relating to the MCA both before, and after, its introduction. On the basis of early work undertaken by members of our group and our collaborators, Tony Holland was appointed as the psychiatric adviser to the Joint Houses of Parliament Scrutiny Committee of the draft Mental Incapacity Bill (chaired by the late Lord Carter). He has continued as an adviser to the Office of the Public Guardian, and, like Isabel Clare, acts as an adviser to third sector and statutory organisations. We have been commissioned by the Department of Health to undertake research on the introduction of IMCAs, on IMCAs and safeguarding, and the interface between the MCA’s Deprivation of Liberty Safeguards (MCA-DoLS) and the MHA. All these reports are publically available. While our principal specialism is that of learning disabilities, we have treated, supported, and/or carried out research with other groups of individuals who may be at particular risk of lacking capacity to make one or more decisions for themselves.

1.2 We welcome the opportunity to make this submission, which draws upon both our research and our experience as clinicians. Details of peer-reviewed academic publications, which have formed the basis of book chapters and other materials for trainees in our disciplines, practitioners in health and social care, carers, and managers and support workers in social care settings are attached as Appendix I. Other materials are available through our website or by contacting us.

2.0 Overview

2.1 We remain strongly of the view that the MCA, which sets out a framework encompassing a very broad range of decisions, is sound and innovative legislation. It seeks to address issues that have often been, and will remain, contentious because they relate to an individual who is, at that time, vulnerable; involve decisions that may be ethically challenging; and about which there may be diverse and indeed opposing views. It seems inconceivable that there could be any return to the uncertainty of the case law or the potential abuses of guardianship legislation. However, we believe that there are some conceptual and practical issues that the Committee may wish to consider. The most important are set out below.

3.0 Conceptual issues

3.1 The principle that adults have the right to make decisions about their own lives is accepted legally and ethically. There needs be some means for proceeding, therefore, when someone cannot understand the nature of what is being asked, make a decision about a course of action and/or communicate her views by some means. In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
means. An obvious, if extreme, example is that of the unconscious patient: if consent were to be required in order for treatment to take place, nothing would happen. The same may be true where someone is extremely intoxicated, or has advanced dementia, or is in severe pain. We accept that an individual with capacity has the right to refuse treatment or have life-sustaining treatment withdrawn. However, when a person lacks capacity to make these decisions, we do not think they should be made on her behalf without stringent safeguards; we must not deny her right to life. The MCA requires of those involved an appreciation of the need to protect and to balance competing rights.

3.2 Concerns have been raised about the inclusion in the MCA of an ‘impairment of, or a disturbance in the functioning of, the mind or brain’ as a necessary, but not sufficient, factor for determining a person’s capacity to make a particular decision. Its inclusion, it has been argued, is discriminatory, but the alternative is that decision-making might be challengeable at any time, perhaps for reasons that are spurious. We should not wish to see the return of a ‘status’ approach (for example, a diagnosis of severe mental health problems) as a lawful reasons to limit adults’ right to make decisions for themselves. The MCA’s principles state very clearly that the starting-point must always be the presumption of capacity. Moreover, the fact that the MCA may, under the appropriate circumstances (for example, following a car accident) apply to any of us rather than simply to a variety of groups with particular diagnoses (such as that of a learning disability) is, we believe a powerful argument against any charge that it is discriminatory. Nevertheless, greater knowledge and understanding of decision-making in the general population is still needed to ensure that the threshold for capacity for those who are assessed under the MCA is not set too high; that would be discriminatory.

3.3 We have made some particular recommendations in our report about the MCA-DoLS and its interface with the MHA. While some of the practitioners who took part in our research recognised benefits to the legislation in care homes, the conceptual point we wish to make here is that in hospital settings, and particularly in psychiatric hospitals, there seems to be limited understanding of its human rights implications. Among many practitioners, the MCA-DoLS was viewed as providing as a legal framework to justify deprivations of liberty; there was limited consideration of the way in which modifications to the person’s social and physical environment might avoid the imposition of a deprivation.

3.4 While we recognise that the timing of the progress of the Bournewood case through the Courts and of what is now the MCA through Parliament meant that the Government had no opportunity to address the violations of Art. 5 of the ECHR as part of the ‘parent’ legislation, the DoLS part of the MCA is practically, as well as conceptually, complex: the procedure is cumbersome; applications for authorisation are dependent on managing authorities; the legislation is not sufficiently closely linked to the principles of the MCA leaving uncertainty about its relationship with the MHA; there is a gap for young adults because the safeguards apply only to those aged 18 years of more; the safeguards apply to care homes and hospitals but not to supported living; and, perhaps worst of all, our findings suggest that the safeguards may not protect the very people (assenting patients in hospital who lack capacity to make decisions about the arrangements for their care and treatment) for whom they were designed. We think the MCA-DoLS merit further consideration. We believe
that they should, however, remain as part of the MCA. While the MHA has a more robust review system, the MCA applies to anyone with an ‘impairment of, or a disturbance in the functioning of, the mind or brain’, not just those with a ‘mental disorder’, and has a focus on the concept of decision-making capacity and sound ethical principles.

3.5 While Articles 5 and 8 of the ECHR have received considerable attention in the context of the MCA, little has been made of Article 6. Under Art. 6, individuals must have access to the courts for decisions about civil obligations. The judgement in the Neary case rekindled concerns dating back to Bournewood, where, if Mr HL had not had paid carers who were willing to challenge his care and treatment, his admission to hospital might never have been subjected to scrutiny. As Neary illustrates, even where family members or others believe that some course of action taken under the MCA is not in fact in the best interests of the person who lacks capacity, concerns about the removal of support or some other adverse outcome may result in their being reluctant to consider any legal challenge. The point we wish to emphasise is that a person whose capacity is so compromised that she is unable to make the relevant decisions for herself is unlikely to know of her right to challenge and be able to exercise this right. At the same, family members who may wish to submit a challenge on her behalf may be reluctant to do so. The MCA needs to be incorporate a robust system of review and, if necessary, challenge, without being burdensome.

4.0 Practical issues

4.1 From the perspective of members of this group with responsibilities for training, the impression is that considerable progress has been made since the introduction of the MCA. Today’s junior doctors, and their colleagues in other disciplines, are much more attuned to the concepts of capacity, decision-making, and best interests than their predecessors. Nevertheless, there is more to do. In some places, there remains a lack of awareness of the full scope of the legislation and a continuing belief that it is limited to people with learning disabilities or dementia. The setting in which the MCA most often needs to be considered is in the Accident and Emergency Departments of general hospitals, where many patients who are admitted are in a state of shock or are, confused, intoxicated, or unconscious. As we have shown (Jacob et al., 2005) engagement with these patients, where it is possible, can both support them to gain or regain capacity to make their own decisions about the treatment required for their condition and to consent to that treatment.

4.2 On occasion, judgments about an individual’s capacity to give or withhold consent may need to be made immediately. Much more often, however, there is at least some time and, if there is uncertainty about the person’s capacity, there are opportunities to enhance her knowledge and understanding of the relevant information, her ability to make a choice, and/or her communication. Sometimes, this may involve simplifying, or breaking down the decision into smaller steps, or making it as concrete as possible; at other times, it will involve more general development of a person’s skills and confidence in making her own decisions and experiencing, in a safe way, their consequences. We wish to emphasise the principle that ‘all practicable supports’ must be offered to assist an individual to gain, or regain decision-making capacity. In some situations, capacity assessments merge into best

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interests decision-making in that, in seeking to establish someone’s person’s capacity to make a specific decision, her wishes and feelings, beliefs and values, will become evident.

4.3 We are, however, concerned that there are times when a person’s capacity to make a decision for herself is used by service providers to abrogate their continuing responsibilities. This may particularly be the case in demanding settings such as emergency departments in general hospitals or social care settings where support staff are concerned they might be blamed for any adverse consequences to the person or others. ‘It’s their choice’ is a refrain that we hear too often. Health and social care practice in mental health, intellectual disabilities, services for older people and other settings in which people with complex needs inevitably involves a delicate and nuanced balance between supporting decision-making and protection from harm. The fact that someone who may be vulnerable and at risk of harm to herself or others has made an apparent reckless but capacitous decision places an even greater responsibility on services to seek to provide support, however difficult that might be.

4.4 More generally, we are concerned about how judgments are made with respect to best interests. We are very supportive of the basic framework set out in the MCA and its Code of Practice. Our concerns relates to two main issues. First, there seems to be some confusion about the priority to be given to different factors in considering a person’s best interests in relation to a particular decision. These factors include not only the ascertainable views of the adult who lacks capacity but also those of others who care for or about her. In contrast with most situations in which someone has the relevant decision-making capacity, its absence means that the person’s views are not determinative. Instead, according to the MCA, her views, as far as they are ascertainable, must be balanced against other factors. There have been examples where, we believe, the right balance has not been achieved. For example, in the Neary case, very limited, if any, consideration appeared to have been given to Mr S. Neary’s wish to return home. At the very least, his views should have been acknowledged, with an account of the reason that acting on these views would not be in his best interests and could not be followed. A second example, which has been addressed in a Court ruling, but may still be contentious, relates to the person who lacks the capacity to consent to life-saving treatment and whose carers believe would resist that treatment. In such a case, some judgment needs to be made about the value to be placed on the person’s putative resistance. We believe that there is an obligation to seek ways to make the intervention possible. Decision-makers in these complex situations need to be aware of the tension between a person’s right not to be subjected to treatment that is degrading and her right to life. In such a case, as in many others, establishing best interests is a process, rather than a decision to be made at a single meeting. People do not always respond in ways that even those who know them well predict and their responses can sometimes be ascertained only through trying out one or more particular courses of action.

4.5 Secondly, and relatedly, we have concerns about the judgments made about the best interests of those with lifelong and severe disabilities who may always have lacked capacity to make some or most decisions for themselves. Research we carried out in social care settings (Dunn et al., 2010) suggested that staff used their own conception of a ‘good life’ as the starting-point for making decisions on behalf of individuals. In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
people with severe learning disabilities. Rather than making a call for more rigorous training, we believe that these workers should be encouraged to think more critically and reflectively about the well-being of those whom they support and how best this might be enhanced. While we are critical of the MCA-DoLS, one of its reported benefits was that, in care home settings, is that it provides some opportunity for support workers and their managers to consider how the freedom of individuals who lacked capacity in relation to decisions about the arrangements for their care and treatment might be less restricted.

5.0 Conclusions

1. We support the MCA. While there is still a good deal of progress to be made, the legislation and the programme of dissemination with which it was accompanied have brought about a cultural sea-change in the lives of adults who lack capacity to make one or more decisions for themselves.

2. We are supportive of the MCA-DoLS from the perspective that some legislation is needed to protect the rights of vulnerable people and to prevent the deprivation of liberty that is not in an individual’s best interests or authorised by some other means, such as the use of the MHA. The difficulties in hospitals settings largely reflect the different principles of the MCA and the MHA. We believe that there is a case for the MCA to be used to address all matters relating to decisions made on behalf of people who lack capacity to make one or more decisions for themselves. The MHA might then be reserved, and arguably limited to forensic settings, for treatment of a mental disorder in individuals who have the capacity to consent but withhold that consent. If such a radical approach were to be considered, the protections enshrined in the MCA could be enhanced so that, in certain situations (e.g. where a person was being deprived of her liberty and it was proposed to that she should receive serious medical treatment), a review system would be activated. However, we recognise that such radical reform is unlikely. Given our view that a deprivation of liberty is as important as serious medical treatment, we believe that an immediate improvement, which would involve some amendments to the MCA-DoLS procedure, would be to provide IMCAs under s. 35 to all those who lack capacity to make a decision about arrangements for their care and treatment and for whom an application is made for authorisation of a deprivation of liberty.

3. With respect to best interests, we believe that there needs to be a better understanding of the way in which the different factors that need to be considered might best be balanced, with more concerted efforts to enable individuals to gain or regain capacity to make decision for themselves as far as possible. We also believe that clinicians and other practitioners would benefit from greater understanding of best interests decision-making, limits to freedom, and their responsibilities towards individuals who make reckless but capacitous decisions within a context that, while consistent with the principles of the MCA, is broader and promotes the well-being of the men and women whom they treat, care for and/or support.

We hope these comments are of some value to the Committee.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Cambridge Intellectual and Developmental Disabilities Research Group, Department of Psychiatry, University of Cambridge – Written evidence

pp. Anthony J. Holland, Health Foundation Chair in Learning Disabilities; Hon. Consultant Psychiatrist
Isabel C.H. Clare, Consultant Clinical & Forensic Psychologist; Affiliated Lecturer
Marcus Redley, Senior Research Associate.


Appendix I

This submission has been informed by interdisciplinary research undertaken by our research group and our collaborators over many years. Listed below is a selection of peer-reviewed publications.


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Cambridge Intellectual and Developmental Disabilities Research Group, Department of Psychiatry, University of Cambridge – Written evidence


29 August 2013

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Camden Safeguarding Adults Partnership Board – Written evidence

Introduction

Camden Safeguarding Adults Partnership Board (SAPB) is a well-developed partnership of statutory, independent and voluntary organisations. Members include Camden Council, Camden Clinical Commissioning Group, Metropolitan Police (Camden), London Fire Brigade (Camden), the Royal Free Hospital, University College London Hospital, Camden and Islington Mental Health Foundation Trust, London Ambulance Service (Camden), Central and North West London NHS Trust – Camden Provider Services, London Probation Service (Camden and Islington), service users and voluntary sector organisations.

Camden SAPB was established under No Secrets (DH: 2000) to coordinate how agencies across the borough work together to prevent abuse and protect adults who may be at risk of harm. Camden SAPB believes considerations of mental capacity are integral to the effective safeguarding of adults, and therefore the Mental Capacity Act 2005 (MCA) is an essential tool in our work to stop abuse.

Camden SAPB supports the drive to examine whether the Act has been effectively embedded in every day practice, understood by professionals and the public, and changed the culture of care. We have particular concerns about the consistency and depth of understanding of the Act by all professionals. We are also concerned that the public and those affected have not been given adequate understanding. We feel that the complex administrative basis of DoLS needs revising, to help the Act achieve its aims.

Camden SAPB’s response to the Select Committee’s specific questions

1. To what extent has the Mental Capacity Act 2005 (MCA) achieved its aims?

1.1. The MCA has achieved the aims of:
• Raising the profile of people who lack capacity who need protection, especially in the decision-making process.
• Legislating many common law principles.
• Providing a clear legal framework around decision-making for those who lack capacity and, if correctly followed, ensuring they are supported to make decisions or that decisions made on their behalf are in their best interests.
• Enabling the Corporate Deputy to authorise (through the best interests decision-making process) a broader range of financial decisions that the previous Court of Protection appointed receiver.

2. Which areas of the Act, if any, require amendment; and how?

2.1. In section 4 (assessment of capacity) the question of fluctuating capacity vis-a-vis the vulnerable patient having the capacity to understand the decision but not fully understand the risks needs amendment. There should also be clarification of what

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constitutes “every day decisions” – this should be made more explicit to provide guidance to staff.

2.2. MCA and DoLS legislation currently omits an explicit power to convey and return a person to a place of residence, nor provides any clear guidance as Guardianship and the Mental Health Act do. This causes confusion amongst professionals when facing challenging situations related to conveyance.

2.3. Schedule A1 of the Act (DoLS) has always caused difficulty in their interpretation and use. They are poorly understood by those who need to know about them, in particular hospital and care home staff. But even where they have been studied in detail (e.g. by solicitors, social workers and medical professionals) there is still a considerable difference in understanding. This is reflected in the considerable variation in DoLS activity across the country – referrals for standard authorisations and proportions of assessments leading to authorisations.

2.4. The eligibility requirement set out in Schedule 1A causes confusion and conflict amongst professionals, and highlights a difference in thresholds between the application of the Mental Health Act and DoLS. The wording of the Act makes it difficult to interpret, where DoLS applies, and whether DoLS or detention under the Mental Health Act is less restrictive. It can result in low rates of DoLS applications from mental health, making it likely that there are a number of people in such settings who lack capacity but are not being protected. DoLS should not apply to mental health settings: the use of the Mental Health Act by these settings should be promoted for those who lack capacity.

2.5. A specific definition of Deprivation of Liberty is missing, which often confuses professionals and they therefore they are unaware when the threshold for Deprivation of Liberty is being indicated. There is also a concern that the process for DoLS does not sufficiently address the need for a speedy review of a person’s detention by a court. The Mental Health Act has a much simpler and speedier process of independent review of detention via the mental health tribunal.

3. At the core of the MCA are its principles and definitions of capacity and best interests. Are these appropriate?

3.1. In part. Although the two definitions of capacity are clear and succinct, the four function test can fail. This may be due to the person asking the questions not having the right expertise, due to questions being poorly framed, or due to other professionals (e.g. GPs) appearing reluctant to provide evidence.

3.2. In addition, the principle of assisting people to make decisions (and not determining that they are unable to make a decision until all practicable steps have been taken) is sometimes given less focus than the capacity and best interests principles and definitions.

4. To what extent have the five principles of the MCA been implemented in frontline practice? What evidence is available to assess this? Is there a satisfactory balance between enablement and protection?

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
4.1. The five principles have been better implemented in frontline practice in some sectors than others. Although, overall, health and social care professionals are aware of the principles and definitions, the depth of knowledge and understanding is patchy across the different sectors/ professions (see Q6).

4.2. We have seen examples of good practice in compliance with the code, such as imaginative methods of providing information to the relevant person, using a variety of visual aids, postponing assessments until necessary audio equipment in available etc.

4.3. However, in some settings (such as large health settings) it does not appear that the culture of decision-making has changed significantly, evidenced by low referrals for DoLS and IMCA and low numbers of best interests meetings held. More work is needed to achieve this cultural shift. In particular, doctors (especially older Consultants) continue to be unaware of the changes, whilst the MCA is still not fully integrated into the pre-registration curriculum for both nursing/midwifery and medical training. Adult safeguarding training is usually included in mandatory training programmes, but it is rare for MCA training to be mandatory. Despite this, most frontline health staff in Camden have received basic MCA awareness training, yet still struggle with implementation in day-to-day practice given the variety of decisions that are required. The Code of Practice in its current form is very detailed and can be unwieldy leaving professionals lacking in sufficient guidance for the variety of real-life complex decisions they face.

4.4. There is an imbalance to enablement and protection, veering more towards protection rather than enablement. This may be due to a risk adverse psyche caused by high profile media cases and a paternalistic attitude towards people at risk.

5. How effective was the Government's implementation plan? What measures were taken to ensure that professionals and families of those who lack capacity know about and act in accordance with the provisions of the MCA? Has it led to sustainable change?

5.1. Limited in effectiveness. Funding was available for a time period but was dedicated to Adult Social care (ASC). Although ASC made training widely accessible, funding for a dedicated professional for health would have helped to embed the law in practice.

5.2. The implementation of the plan for Deputy work and new Court of Protection application procedures have significantly increased the administration and resources required. The time required for court order processing results in delays in accessing finances, and delays in financial abuse investigations. Families have not been given enough information about the Act.

6. Is the Act widely known and understood by professionals required to implement it? How does this differ across different sectors, such as health, social care, banking and others?

6.1. Six years on there is considerable variation between and within different professional groups in the depth of their MCA understanding. It has been embedded in order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
better with some professionals that with others. For instance, we have found that in general social workers have a better understanding of the MCA that most other health and social care professionals, because the decisions they are involved in are generally longer term and require significant planning and consideration. Social care processes appear to act as a check and balance mechanism to ensure the Act is being followed and used appropriately. Yet there are still some social care professionals who do not understand the concepts of capacity and best interests, and in addition many professionals lack confidence in applying what they do understand of the Act demonstrated in a frequent reluctance to assess capacity.

6.2. In health settings the Act is known about but the level of understanding is not as deep – the MCA may be seen as social care legislation. A proportion of GPs and medical staff need improved knowledge of the Act, e.g. some GPs and nurses have been reluctant to complete COP3 forms even though they have the expertise and are clearly the most appropriate person to undertake this role. In large health organisations with MCA leads and policies/procedures, implementation has been more robust.

6.3. In addition the existence of the MCA is not widely known or understood by those outside the health and social care professions. For instance, bank and building society staff rarely understand Duty Orders and unregistered EPAs. But most importantly, the MCA is not understood by those affected by the Act or those caring for an affected person.

7. Is the Act widely known and understood by those who are directly affected by it and by their non-professional carers? To what extent does the Act provide protection and reassurance for informal carers? Has the right balance between protection of the carer and protection of the individual lacking capacity?

7.1. As stated above, whilst most non-professionals are aware of the concept of capacity, there appears to be little awareness of the actual legislation and its purpose. It has not provided much support or protection to those affected by it and their non-professional carers. The balance has not been struck.

8. Has the Act ushered in the expected, or any, change in the culture of care?

8.1. Apart from a positive increase in mindfulness of the Act regarding financial management, Camden SAPB feels the MCA has not ushered in a change of culture in care.

9. Is there any evidence that the provisions of the MCA affect some groups disproportionately? If so, what data exists to compare representation across different socio-economic groups, Black and Minority Ethnic groups, and gender?

9.1. From data collected since April 2011, white people appear to be the most likely to undergo an assessment of capacity (86% of assessments), 88% of whom were found to lack capacity. However, ONS statistics suggests the area demographic of this particular group is 66% - so white ethnic groups are over-represented in capacity assessments, possibly due to older adults being more likely
to be affected by dementia and loss of cognitive function and this age group containing a higher proportion of people with white ethnic backgrounds than the rest of the population. At present it does not appear that Black and Minority Ethnic groups are under-represented in capacity assessments or amongst those assessed as lacking capacity. The same appears to be true of gender.

10. Are those directly affected by the Act being enabled and supported to make decisions for themselves to a greater or lesser extent than they would have been in the past? Does the means by which the decision is made – ‘general authority’, Lasting Power of Attorney, deputyship, Court of Protection – affect the quality of decision making?

10.1. Health settings feel the MCA has made a small positive difference to people who have learning disabilities, especially in terms of supporting and enabling them in the decision-making process.

10.2. Overall however it is difficult to draw a comparison between whether people are better enabled or supported than previously. What the act has done is to ensure that decisions are evidenced-base, that evidence of customer involvement in decision-making is recorded, and that professionals are more aware of the decision-making process. The best interests decision-making process is an area that requires further development.

11. What evidence is there that advance decisions to refuse treatment are being made and followed?

11.1. No comment

12. Has the MCA fostered appropriate involvement of carers and families in decision-making?

12.1. Overall it is felt that yes, carers and families are appropriately involved in decision-making through effective case management.

13. Has the role of the Independent Mental Capacity Advocate (IMCA) succeeded in providing a voice for clients and an additional safeguard against abuse and exploitation for those who have no-one to speak on their behalf?

13.1. Overall IMCA support has been valuable, especially in contentious cases, in giving a voice for the vulnerable person, providing evidence for best interests decisions, and ensuring confidence in decisions as IMCAs are independent. However, there is a risk that an IMCA can promote a view they know will be in accordance with what professionals want to hear. Any guidance issued for IMCAs should ensure there is a focus on the individual’s view point.

14. Has the level of referrals to IMCAs met expectations? What are the reasons for the regional variations in the number of referrals?

14.1. IMCA referrals have risen steadily in Camden year on year, however the level of referrals to IMCA in adult protection cases remains low. Low numbers of referrals may be due to local interpretation of the law by multi-agency partners.

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Local statistics show that there are very few challenges to decisions, both in terms of the Act and Schedule A1, which would appear to support national figures.

15. Are IMCAs adequately resourced and skilled to assist in supported or substituted decision making for people lacking capacity?

15.1. Multi-agency partners feel the level of training and knowledge of IMCAs is still variable, and that IMCAs do not always understand different partners’ ways of working meaning they are less able to effectively engage with us on their client’s behalf.

15.2. IMCAs do not having a common validated academic pathway and qualification. This also applies to BIAs. Apart from guidance provided by SCIE, there does not appear to be any national standards or regulatory body that ensure that consistent professional standards are being applied. The role of monitoring IMCAs falls to the local commissioning body and individual IMCA providers, hence the variation. We would like to see national standards set for the IMCA role which are transparent and allow a pathway of recourse to address any issues arising. We would also like to see the IMCA role be regulated by a central body as other professional groups are.

16. Are the safeguards in the Deprivation of Liberty Safeguards (DoLS) adequate?

16.1. This is difficult to state, as it may be that the safeguards are inadequate, but equally it may be the implementation that has been inadequate whilst the safeguards themselves are fine. A key issue is that despite four years of DoLS implementation, social care and other professionals involved in a person’s care still seem to be misunderstanding DoLS, lacking confidence in applying it and, in some instances, confusing it with the Mental Health Act. The DoLS process and language is complex – alienating professionals and individuals alike.

16.2. The wording of the code of practice and legislation suggests that managing authorities make the sole decision as to whether to deprive someone of their liberty. Managing authorities often do not see themselves as depriving someone of their liberty and find it difficult to accept that this is what they might be doing when providing care for an individual. For care homes a deprivation of liberty is often the result of a care plan devised by a social worker, which the home is required to implement. Yet social workers often view DoLS as something separate from their work and may not understand that their care plan results in a deprivation of liberty for that person and subsequently may not understand their on-going role when an authorisation is granted.

17. Are the processes for authorisation, review and challenge of DoLS sufficiently clear, accessible and timely?

17.1. Whilst administratively cumbersome, DoLS has been able ensure that the rights and freedoms of individuals are protected. The assessment process within the Safeguards provides an opportunity for a thorough independent, objective examination of complex situations, which may have been on-going for several months or years. Normal community care assessments and mental health

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assessments do not prompt the level of investigation that is required by the DoLS Assessment process. DoLS also provides a mechanism for on-going monitoring where an authorisation is granted.

17.2. However, both hospitals and care homes continue to be confused by the DoLS process. They struggle to understand the different types of applications, the burdensome forms often asking for duplicate information, and the terminology of the DoLS process. This may put them off making applications, or mean they need to be coached through them or that the supervisory body has to go back to the managing authority to fill in missing/incorrect information. For instance, one nursing professional recently stated they had heard of DoLS but did not know they needed to make a formal application. The application process can take a significant amount of time and resources – sometimes several days from point of notification.

17.3. The competing timescales can confuse managing authorities, assessors and supervisory bodies. The seven day timescales attached to urgent authorisations often do not give sufficient time to collect and analyse evidence from the required variety of sources, and thoroughly examine the circumstances. This can result in rushed decisions, which might be different if more time were allowed. Managing Authorities do not understand the purpose of a review and when to request one. They often require prompting to make a request, and substantial support to understand the reasons for the review and the implications of non-compliance.

17.4. The role of the representatives is not fully understood, especially in terms of acting in the person’s best interests and challenging authorisations. Managing authorities do not always understand their monitoring role, and a supervisory body may be unaware of difficulties until the authorisation is ending. In addition, Representatives often do not understand their role with regards to monitoring of the authorisation.

17.5. The Safeguards would be adequate if the processes were made simpler and clearer; in particular clearer definitions of a deprivation of liberty, and enforceable sanctions against managing authorities not complying with requirements. If the process is changed, it is essential that any replacement procedure ensures that the Best Interest Assessment remains an essential part of that procedure.

18. Are the Court of Protection and the Office of the Public Guardian sufficiently understood and accessible to all? Are they operating effectively and successfully?

18.1. Adult social care professionals are less familiar with court applications and processes than mental health and children’s social care services, and health settings rarely make applications. The threshold for when a case requires an application to court is not clear and the application process is very complex – different forms, duplicated information and unhelpful timescales.

18.2. There is a lack of specific guidance to supervisory bodies in respect of S21a applications where the only person objecting is the relevant person. In most cases the relevant person or their representative does not understand their responsibility for making an application to court, nor the mechanism for doing so. For those who continue to object to their detention but do not have the ability to understand how
Camden Safeguarding Adults Partnership Board – Written evidence

to initiate an appeal, it is not clear who this responsibility then falls to, leaving a significant gap and lack of protection for the detained person.

18.3 The Court of Protection is difficult to liaise with on casework. There are sometimes lost forms in the application process, or evidence is split from the application. Fees have to be paid up-front when evidence of an exemption is unavailable. It can take a long time for phones to be answered and email responses can be very limited. A helpline is lacking as is useful advice via the internet site. There is also a lack of practical, technical advice provided to help with the confusion court procedures. It would be helpful if dedicated case workers were reinstated to help case work liaison. Although the Office of the Public Guardian has modernised faster than the Court, the Office has misunderstood the role of the local authority Deputy evidenced by supervision levels on some cases.

19. What has been the impact of the introduction of Lasting Powers of Attorney (LPA), especially with regard to decision making on matters of personal care and welfare?

19.1 In health settings it has helped to clarify the formal position for patients, which is useful. However, as with the discussion above in Q6 and Q7, most of the public and families are not aware of the LPA’s existence, which severely limits its impact.

20. What concerns, if any, are there regarding the costs associated with registering an LPA, or with making an application to the Court of Protection?

20.1 Court of Protection application costs are prohibitively expensive. Social workers feed back that family members who may wish to manage their relative’s affairs are often put off from making an application due to the high costs and the complex administrative process – particularly if they cannot access the relative’s finances in order to fund the application. They will often request that the local authority make the application, particularly in relation to finances or tenancies.

21. Is legal aid available and sufficient? What impact will the recent and proposed reforms to legal aid have?

21.1 No comment.

22. Is the role of the Care Quality Commission in inspecting on the MCA standards adequate and appropriate? Is there a case for additional powers?

22.1 There is a variation in CQC inspections and inspectors’ knowledge. Some inspectors have limited knowledge and are therefore unable to frame questions relevant to the MCA when interviewing staff.

22.2 It would be helpful if CQC had additional powers to address issues where managing authorities appear not to be complying with a DoLS authorisation, as at present there are no significant sanctions or reporting mechanisms for non-compliant managing authorities. It would be helpful if CQC had powers to inspect financial management at care homes and home care providers, and be able to

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recommend alternative provider management where a provider is failing. There is also a gap in un-registered services and organisations – e.g. private carers and providers.

23. Should other regulatory bodies, such as health and social care professional regulators, be acting in this area?

23.1. There is a concern that this may add confusion.

24. How well is the relationship with the mental health system and legislation understood in practice?

24.1. As described above in Q2, there is confusion about the interface between the MCA and the mental health system, and which Act to implement in which scenario.

25. Does the implementation of the Mental Capacity Act differ significantly in Wales?

25.1. No comment.

26. What lessons, if any, can be learnt from the approaches taken to mental capacity legislation in Scotland and Northern Ireland, or in other jurisdictions?

26.1. No comment.

27. Is the MCA compliant with the United Nations Convention on the Rights of Persons with Disability (CRPD)? Are there lessons that can be learnt from the CRPD for the successful implementation of the MCA?

27.1. No comment.

30th August 2013
I am writing in consequence of the discussions held by the House of Lords Select Committee Mental Capacity Act 2005.

1] What precisely is “mental capacity”?

2] What is the precise definition of “mental capacity”?

3] How is “mental capacity” defined?

4] Who defines the definition of “mental capacity”?

5] What percentage of “balance of probabilities” is required to determine whether a person is mentally capacitous?
   Is it a 50-50 split?
   A 49-51 split?
   A 30-70 split?
   A 10-90 split?
   A 1-99 split?

6] How, specifically, is a person assessed to check mental capacity?

7] Who has the training to assess mental capacity?

8] If Mental Capacity assessment is to become seamlessly interwoven in our daily lives, then how will the public be educated so that we all become fully aware of what to look for when determining if a person has lost mental capacity to make their own decisions?

9] The SCIE has published a report that makes worrying reading, as Social Workers have not been able to assess with anything like 100% accuracy people’s mental capacity. As Social Workers are often front-line professionals determining “mental capacity” and they have found it so difficult, is it possible that the Mental Capacity Act 2005 as it currently stands, is incomprehensible to implement totally, as the central tenet is first to define if a person has mental capacity, being time and issue specific, and that a person must be allowed to make an unwise decision even if the assessor would not choose that way for him or herself? This seems to be the major stumbling block in the Act.

10] Judges have found the Mental Capacity Act 2005 difficult to understand, and this is on record. Where a law is dense and open to wide interpretation, it becomes very difficult to establish what was in the lawgiver’s mind. Take for example the issue of two people, both of whom have been taken to the Court for a decision. In one case a person has been allowed to die and in the other has been forced to live by being force-fed. Different court, different judge but the same act. This is a matter of life-and-death decision-making and it is extremely complex and one which needs good clear crystal English for the ordinary lay person to understand. This has not happened in our current Mental Capacity Act 2005 I aver.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Thank you very much for this post-legislative review which is most helpful.

Rosemary Cantwell
A member of the public

2 September 2013
Care Quality Commission – Written evidence

The following written evidence has been prepared by the Care Quality Commission (CQC) in advance of our oral evidence session with the Committee on 29 October.

In responding to the Committee’s inquiry, we have focused on those areas where we are able to provide evidence. We welcome the opportunity to appear before the Committee and will give further consideration to other areas of the inquiry in preparation for that session.

This submission covers the following points:

- Overview of CQC
- Overview of the Care Quality Commission’s responsibilities towards the Mental Capacity Act Deprivation of Liberty Safeguards and the Mental Capacity Act
- Answers to questions asked by the Committee where CQC has evidence

Care Quality Commission: Purpose

We make sure health and social care services provide people with safe, effective, compassionate, high-quality care and we encourage care services to improve.

Care Quality Commission: Role

We monitor, inspect and regulate services to make sure they meet fundamental standards of quality and safety and we publish what we find, including performance ratings to help people choose care.

Care Quality Commission: Overview

CQC is the national regulator for health and social care in England. We have distinct responsibilities towards monitoring the operation of the Mental Capacity Act Deprivation of Liberty Safeguards.

In April 2013 CQC launched its new strategy, ‘Raising Standards, Putting People First’, to ensure that CQC operates as a regulator that focuses on putting people at the heart of what it does in a changing health and social care landscape.

At the centre of our new approach is a focus on five key questions that will be asked of providers about their services:

- Are they safe?
- Are they effective?
- Are they caring?
- Are they well-led?
- Are they responsive to people’s need?

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To deliver our purpose we are making significant changes to the way we work and our working with the Department of Health to ensure that the existing regulations effectively capture the areas that will be inspected under the new models. These areas will reflect the five key question; these will include, but are not limited to, the fundamental standards of care. Once agreed, these regulations will be subject to public consultations.

CQC has recently confirmed the appointment of its three Chief Inspectors and changes to the way we regulate acute hospitals are underway, with other health and social care sectors to be taken forward through a phased programme up to 2016. We will hold formal consultations with the different care sectors as we develop our methods.

A central part of changing the way we regulate will be to ensure that the Mental Capacity Act (MCA) is embedded across our regulatory framework. Our written evidence highlights a lack of understanding of the MCA across the health and social care system and we hope to challenge this by ensuring that the principles of the MCA sit at the heart of CQC’s understanding of care quality in the new regulatory models.

CQC understands the importance of the Deprivation of Liberty Safeguards in protecting the human rights of vulnerable people and plans to ensure that our responsibility for monitoring their operation is practically embedded in our new inspection models.

Overview of the Care Quality Commission’s responsibilities towards the Mental Capacity Act Deprivation of Liberty Safeguards and the Mental Capacity Act

How the Care Quality Commission monitors the operation of the Deprivation of Liberty Safeguards

CQC has a duty to monitor the operation of the Deprivation of Liberty Safeguards in England. CQC also has the ability, under the same legislation, to provide advice and information to the Secretary of State on the use of the Deprivation of Liberty Safeguards in England.

A Code of Practice to the Deprivation of Liberty Safeguards sets out expectations for the monitoring role, and says CQC should monitor the Deprivation of Liberty Safeguards through its existing programme of inspections, and report annually.

In fulfilling this function the CQC produces an annual report that reports on the use of the Deprivation of Liberty Safeguards in England. CQC’s most recent report (published March 2013), ‘Monitoring the use of the Mental Capacity Act Deprivation of Liberty Safeguards in 2011/12’, is attached to our submission.

CQC intends to bring forward publication of the 2012/13 report to December 2013 in order to align it more closely with the year that it reports on.

Due to its responsibility for monitoring the Deprivation of Liberty Safeguards, CQC is also part of the UK’s National Preventive Mechanism under OPCAT (the United
Care Quality Commission – Written evidence

Nations Optional Protocol to the Convention Against Torture). The preventive mechanism performs the UK’s obligations under that treaty to prevent torture and other cruel, inhumane or degrading treatment or punishment.

In terms of specific action against concerns arising about use of the Deprivation of Liberty Safeguards during CQC’s inspection activity, it is important to note that there is no enforcement powers associated with CQC's monitoring role. Where CQC finds that the Deprivation of Liberty Safeguards are not being used correctly, this could lead to CQC taking action under the HSCA.

A number of the HSCA regulations contain references to elements of the Deprivation of Liberty Safeguards – for example in the regulations dealing with consent, safeguarding, and general care and welfare.

CQC’s Guidance to Providers sets out the criteria by which the Deprivation of Liberty Safeguards will be integrated into Inspections, and against which outcomes this will be linked to in the individual inspection report that is made publically available on CQC’s website.

Mental Capacity Act Deprivation of Liberty Safeguards: Purpose

The Mental Capacity Act Deprivation of Liberty Safeguards was introduced to the MCA by the Mental Health Act 2007. They were introduced as a result of case that went to the European Court of Human Rights that found an individual had been deprived of his liberty under Article 5 of the European Convention on Human Rights.

The Deprivation of Liberty Safeguards provide a statutory framework for authorising the deprivation of liberty for people in hospitals or care homes who lack the capacity to consent to treatment or care where, in their own best interests, that care can only be provided in circumstances that amount to a deprivation of liberty.

Mental Capacity Act: Purpose and key principles

The primary purpose of The Mental Capacity Act 2005 (MCA) was to empower, and strengthen protection for, those who have lost capacity to make decisions for themselves and to empower persons to be able to make provision for a time in the future when they may lack capacity.

Section 1 of the Act sets out the 5 key principles that the MCA is based on. These are:

• A person must be assumed to have capacity unless it is established that he lacks capacity
• A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success
• A person is not to be treated as unable to make a decision merely because he make an unwise decision
• An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is

How the Care Quality Commission inspects and enforces against the MCA

CQC currently inspects health and social care providers against the MCA in all the sectors that it regulates. During inspections, CQC inspectors are responsible for identifying potential breaches of the MCA in so far as a breach may equate to a failure against current CQC regulations.

CQC’s Guidance to Providers states:

CQC has no direct powers to enforce the MCA, but the Health and Social Care Act 2008 and its regulations have very similar relevant requirements in relation to involvement, choice, decision-making and care planning. These requirements and guidance about compliance with them can be found in the following Essential standards outcomes:

- Outcome 1: Respecting and involving people who use services
- Outcome 2: Consent to care and treatment
- Outcome 4: Care and welfare of people who use services
- Outcome 14: Supporting workers

Failure to comply with the MCA can be taken into account when making judgements about compliance. The provisions of the MCA 2005 can be “relevant requirements” for enforcement purposes.

CQC Guidance to Inspectors states:

CQC has no direct duty or powers to enforce the Mental Capacity Act 2005. However, regulation 18 of the Activities Regulations (Outcome 2 – consent) was amended in June 2012 to require that when a person using a service lacks capacity to take decisions in relation to consenting to the care and treatment, registered persons must follow a process that complies with Section 4 of the Act. […]

In addition, in certain circumstances CQC can take regulatory and enforcement action for failure to comply with relevant similar requirements of the Health and Social Care Act 2008.

For example:

- If people are not being involved in decisions about their care, we can take action in relation to failure to comply with Regulation 17; Outcome 1 - Respecting and involving people who use services.
- If we have concerns about the use of restraint and people’s capacity to consent, we can consider whether regulation 11 is being complied with (Outcome 7 - Safeguarding people who use services from abuse).
We can serve a warning notice and take other regulatory action about any failure to comply with the Mental Capacity Act 2005, which is a ‘relevant requirement’ for Health and Social Care Act 2008 purposes. The MCA also impacts on a number of areas that exceed the scope of CQC’s defined statutory powers under the Health and Social Care Act 2008 (HSCA). CQC jurisdiction extends to those providers of services defined as being under the remit of the CQC in the wording of the HSCA.

Answers to the Questions asked by the Committee

Overview and context

1. To what extent has the Mental Capacity Act 2005 (MCA) achieved its aims?

CQC believes that the Mental Capacity Act 2005 (MCA) has provided the basis for hospitals and care homes (managing authorities) to better understand their responsibilities towards those who may lack capacity. It has helped to clarify the distinction between mental health and mental capacity in terms of people’s needs and corresponding requirements on services. The latter can apply to people receiving care in a wide range of settings including acute hospitals, care homes and the community, as well as those who are receiving care for mental health issues.

Feedback from our inspectors is that the MCA is an important and workable piece of legislation that has the ability to protect vulnerable people. The Deprivation of Liberty Safeguards element provides a level of independent scrutiny (by local authorities in their role as a supervisory body) and an independent review mechanism (in the Court of Protection) to test the decisions made by care homes and hospitals against the highest standards of human rights-based care. CQC’s role in the process is in its duty to monitor the operation of the Deprivation of Liberty Safeguards in England.

The extent to which the MCA may not have achieved its aims is linked to the variable application and understanding of the legislation across the health and social care system. CQC’s annual monitoring report on the use of the Deprivation of Liberty Safeguards has highlighted that there appears to be an increasing understanding of the principles of the Act but this can be variable across care homes and hospitals. Even where there is an understanding of the principles of the Act, there is often a lack of understanding or confidence around the practical application of the principles.

2. Which areas of the Act, if any, require amendment; and how?

1. We do not believe that it is necessary to amend the Mental Capacity Act legislation; either as a whole, or specifically to those parts pertaining to the Deprivation of Liberty Safeguards.
2. Our annual reports have highlighted that there are issues around how the principles of the MCA are applied in practice, including a low understanding of the MCA and the place of the Deprivation of Liberty Safeguards within the Act amongst those providing and commissioning relevant services.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
3. Levels of understanding of the Act vary across providers and commissioners of services and may be a factor lying behind an identified variation in usage of the Deprivation of Liberty Safeguards nationally.

4. We would welcome opportunities to work co-operatively with our partners to improve understanding of the MCA and the Deprivation of Liberty Safeguards across the health and social care system. In our latest annual report we identified a number of recommendations where we feel we could work more closely with others. These included:
   a. Develop its work with local authorities in their role as supervisory bodies
   b. Further develop ways to gather the experiences of people lacking capacity and their family, friends and carers
   c. Continue to promote evidence of what works well

3. At the core of the MCA are its principles and definitions of capacity and best interests. Are these appropriate?

CQC supports the principles of the MCA and the definitions concerning capacity and best interests. They are very much in line with the aim of our strategy to put people at the heart of what we do and provide a legal framework to ensure person-centred, human rights-based care.

The principles empower individuals wherever possible to make their own decisions about care and treatment and ensure the involvement of the individual in decisions even if they lack capacity for certain decisions. They mandate consultation with interested family and friends or Independent Mental Capacity Advocates if a person has no representative of their own. The MCA encapsulates the principle of ‘no decision about me, without me’, a central part of Government health and adult social care policy, for all people who may lack capacity for specific decisions.

Implementation

4. To what extent have the five principles of the MCA been implemented in frontline practice? What evidence is available to assess this? Is there a satisfactory balance between enablement and protection?

It is important to note that the MCA provides no additional powers of inspection or enforcement to CQC outside of the powers already contained in the Health and Social Care Act 2008 (HSCA). CQC does not currently inspect against the five principles of the MCA except where the "best interests test" contained in the MCA is specifically included in a provider’s obligation to act in accordance with service users’ consent, in Regulation 18 Health and Social Care Act 2008 (Regulated Activities) Regulations 2010.

However anecdotal feedback from our inspectors’ experience of inspections is that where care homes and hospitals demonstrate good practice across a number of areas, they are also more likely to be locations where staff, at all levels, feel confident in applying the MCA appropriately.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
This links to the CQC’s commitment to inspect against the 5 key questions that CQC is to embed in its regulatory frameworks – specifically the question as to whether providers of services are well led.

6. Is the Act widely known and understood by professionals required to implement it? How does this differ across different sectors, such as health, social care, banking and others?

We have focussed our comments on the sectors that it regulates and monitors – adult social care, independent healthcare and NHS care. As we do not specifically regulate professionals, our comments represent an overview across hospitals and care homes.

A consistent theme from CQC’s annual monitoring reports has been the often poor level of understanding of the Act by providers and commissioners of services. We have seen this in inspections where there have been failures to involve the individual in care planning, failures to appropriately notify CQC of outcomes of authorisations and the inappropriate use of restraint and other restrictive practices.

Restrain and restrictive practice can cover a wide array of activities from physical restraint to locking bedroom doors to stop patients freely moving around. It can also manifest in the use of blanket policies to manage individual patients and create situations that are effectively de facto detention, for instance ‘nine patients were informal and thus should be free to come and go from the ward. However there was a coded lock on the door and the code was not on display for those who have capacity. This could be seen as a deprivation of liberty matter’.

It must be stressed that these failures of understanding are variable across the system. Feedback from our inspectors is that a care home or hospital that provides a good level of care is also likely to have staff who understand the MCA, how it relates to the MHA and when it is appropriate to apply for a DoLS authorisation. Alternatively if a provider is providing poor care quality across a number of areas, it is also less likely that staff feel confident using the MCA or can demonstrate its principles in their actions.

Among care staff there often remains a culture of seeing the whole area of capacity, including assessment, as a ‘professional’ issue and outside their role either to carry out an assessment or to challenge the assessment of a doctor or a social worker.

7. Is the Act widely known and understood by those who are directly affected by it and by their non-professional carers and families? To what extent does the Act provide protection and reassurance for informal carers? Has the right balance been struck between protection of the carer and protection of the individual lacking capacity?

CQC continues to explore ways to elicit the views of people involved in the Deprivation of Liberty Safeguards, either directly or as unpaid Relevant Person’s Representatives. As part of the inspection process, CQC seeks the views of relatives and friends of those using services: feedback from inspectors suggest that informal

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carer rarely understand that, as part of the statutory best interests decision-making process included in the MCA, they have a legal right to be consulted.

8. Has the Act ushered in the expected, or any, change in the culture of care?
CQC does not have the evidence to state whether the Act has ‘ushered in the expected, or any, change in the culture of care’.

However feedback from our inspectors suggests that where staff, at all levels, understand and have confidence in applying the principles of the Act it is more likely that the care being provided is person-centred. This means that individuals would be involved in the development of their care plans and where possible their preferences are accommodated and/or their best interests are met.

Deprivation of Liberty Safeguards

16. Are the safeguards in the Deprivation of Liberty Safeguards (DoLS) adequate?

As CQC has highlighted in its annual monitoring reports, the primary issue is one of a lack of understanding of the MCA, and by extension the Deprivation of Liberty Safeguards. If the ‘5 key principles’ and the concepts of ‘capacity’ and ‘best interests’ (as defined in the MCA legislation) are properly understood by those working at all levels of the health and social care system then the Deprivation of Liberty Safeguards would be adequate.

CQC has no enforcement power under the MCA, or under the DoLS. We can take action against care homes and hospitals through our enforcement powers under the HSCA but only Regulation 18 is directly applicable to the MCA (as explained in CQC’s response to Question 4).

Any other failures to apply the Deprivation of Liberty Safeguards, and hence the breaching of a person’s human rights, must be enforced through alternative regulations, such as those relating to consent, safeguarding or supporting workers. It could be argued that this may limit their perceived importance.

CQC does not have statutory responsibility for how supervisory bodies discharge their own responsibilities under the Deprivation of Liberty Safeguards. Supervisory bodies have a key assurance and quasi-judicial role in the DoLS system and so it is important to ensure that some oversight over their activities is maintained. In CQC’s last annual report on the operation of the Deprivation of Liberty Safeguards, we reported a pilot project that highlighted variation in how supervisory bodies discharge their responsibilities. This included how they supported care homes and hospitals, their relationship with Safeguarding teams and working with advocates.

As the regulator for health and social care in England, CQC has assumed a more collaborative approach to this issue. CQC has worked in partnership with local authorities to carry out projects that provide an improved national understanding of how supervisory bodies operate, and where necessary has contacted individual authorities to remind them of their responsibilities under the Deprivation of Liberty Safeguards.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
CQC believes that a collaborative approach based on sharing good practice would be the optimal solution — with the cooperation of local authorities — but it remains to be further tested as to whether this provides appropriate safeguards in the system.

17. Are the processes for authorisation, review and challenge of DoLS sufficiently clear, accessible and timely?

We note concerns that have been raised about the processes surrounding authorisation, review and challenge of a DoLS application. Hospitals and care homes are required to notify CQC about the outcome of applications for authorisation and our previous monitoring report flagged up the issue of under-reporting of notifications to CQC. This could be symptomatic of the wider issue concerning a general lack of understanding of the MCA and the Deprivation of Liberty Safeguards.

We are concerned by hospitals and care homes failing to understand their responsibility to notify us as part of the oversight process, and we are developing its monitoring of the Deprivation of Liberty Safeguards to further tackle this issue. We have used data to identify specific areas of under-notification and have begun writing to local authorities to remind them of their responsibilities towards care homes and hospitals, and to ask them to investigate the cause for under-notification.

In cooperation with the Health and Social Care Information Centre, CQC is planning to explore the use of DoLS authorisations relating to individuals over a time period. This will cast a light on individuals who may have been lawfully detained under a series of authorisations for a considerable time, in some cases since the initiation of DoLS in 2009.

This situation may reflect the real difficulties of protecting the human rights of a small group of people who lack capacity to consent to arrangements for their care, and whose behaviour may cause such serious risk to themselves that the necessary restrictions to keep them safe amount to an appropriate usage of a deprivation of liberty application.

The CQC is aware of cases where the Court of Protection has criticised supervisory bodies for using DoLS inappropriately to try to legitimise a breach of European Convention of Human Rights’ Article 8 which provides the right to liberty and security. It is an area that continues to develop through the precedence set by Court judgements.

We welcomes any guidance that reminds supervisory bodies that any intractable dispute between a local authority or NHS body and the relatives or friends of a person lacking mental capacity must be referred to the Court of Protection for determination.

Regulation

22. Is the role of the Care Quality Commission in inspecting on the MCA standards adequate and appropriate? Is there a case for additional powers?

CQC currently inspects health and social care providers against the MCA in all the sectors that it regulates. During inspections, CQC inspectors are responsible for identifying potential breaches of the MCA in so far as a breach may equate to a
Care Quality Commission – Written evidence

failure against current CQC regulations. CQC has no direct duty or powers to enforce the MCA.

There are two key limitations to CQC’s powers in relation to the inspection of the MCA standards. These are:

I. Jurisdiction

CQC’s powers of enforcement are limited to the services that we regulate, whilst the MCA has a much wider application. It would not be appropriate to regard CQC as the body “inspecting on the MCA standards” across the board. They apply in other care services, such as banks and educational settings, and we are not in a position to comment on these environments.

CQC should not take on responsibility for inspecting MCA standards in these other sectors.

II. Enforceability of the Requirements

Even within the care settings we do regulate, (apart from the role CQC has as the monitoring body for the Deprivation of Liberty Safeguards) CQC has no specific inspection remit under the MCA except in so far as its requirements coincide with the HSCA and the associated regulations. As part of transforming our inspection models we plan to embed the MCA across the five key questions – are they: safe, effective, caring, well led and responsive to people’s needs? - in order to ensure that it informs our key lines of enquiry during inspections.

There is one specific place where the MCA and the HSCA overlap – Regulation 18 Health and Social Care Act 2008 (Regulated Activities) Regulations 2010 requires a registered person to consider the best interests test set out in Section 4 of the MCA as it ensures that care is delivered in accordance with the capacity and/or consent of service users. This means that, as part of assessing whether a provider has met the necessary standards, we must specifically consider whether the Section 4 tests have been carried out.

CQC is currently working with the Department of Health over changes to the regulations to ensure that they reflect the changes that we will be making to the way we inspect and assess care quality. These will be subject to public consultation before any changes to the existing regulations are finalised.

CQC believes that sufficient authority lies in its existing powers, which will be reinforced by amendments to current regulations relating to quality of care, to inspect against the MCA standards in health and social care settings.

23. Should other regulatory bodies, such as health and social care professional regulators, be acting in this area?

As CQC’s jurisdiction is limited it may be appropriate for MCA requirements to be included in the remit of other regulators. We would welcome discussions with

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professional regulators to explore whether it would be appropriate for them to become more active in this area.

Other legislation

24. How well is the relationship with the mental health system and legislation understood in practice?

CQC does not believe that the relationship between the MCA and legislation that covers mental health is well understood by those responsible for implementing it. Whilst there are providers of services who demonstrate good practice, CQC has previously identified in its annual reports on the Deprivation of Liberty Safeguards examples of the MCA and the MHA being used inappropriately.

There are elements of the MCA and the MHA that should in practice complement each other. The MHA (broadly speaking) provides a basis for the treatment of mental disorder in specified circumstance where individuals present particular risks to themselves or others, while the MCA provides a mechanism for making decisions with or on behalf of people lacking capacity that may or may not apply within a mental health setting.

When decisions are made to deprive a person of their liberty, the decision of which Act takes precedence or has application is sometimes regarded as highly complicated, and hence poorly understood.

In addition there is a wider issue of how the legal framework for the regulation of health and social care environments operates coherently. This includes the MCA and MHA legislation and their relationship to the Health and Social Care Act.

The impact of the current Care Bill also needs to be considered, alongside changes to the planned regulations due to the introduction of the fundamental standards.

10 September 2013
TUESDAY 29 OCTOBER 2013

Members present

Lord Hardie (Chairman)
Lord Turnberg
Baroness Andrews
Baroness McIntosh of Hudnall
Baroness Barker
Baroness Hollins
Lord Swinfen
Lord Alderdice
Baroness Shephard of Northwold
Lord Faulks

Examination of Witnesses

David Behan, Chief Executive, Care Quality Commission, Rachel Griffiths, Mental Capacity Act Policy Manager, Care Quality Commission, and Andrea Sutcliffe, Chief Inspector of Adult Social Care, Care Quality Commission

Q197  The Chairman: Good morning and welcome to this evidence session. I am sorry we are a few minutes late in starting your evidence. Could I just remind you that the evidence is recorded and transcribed?

Could I start by asking how the Mental Capacity Act features in the delivery of your functions? How do you relate to others with regulatory or inspection functions with regard to the Act?

David Behan: Thank you, Chair. I am delighted to be here to assist you in your review. I am joined by Andrea Sutcliffe, who has just joined us as Chief Inspector of Adult Social Care, and Rachel Griffiths, who is occupying a post in mental capacity, so we are building our capacity in relation to this work. Any questions that are too difficult for me, Chair, I am going to pass on to my colleagues and they will be able to answer them, I am sure.
To come to your question, we have an important role. Our purpose is to make sure that health and care services provide people with safe, effective, compassionate, high-quality care. We do that so services can improve; we encourage services to improve.

Within that, our responsibilities under the mental capacity legislation are to monitor the implementation and delivery of that legislation. We do that through the inspections we undertake and, as part of our inspections, we assess how far services are using the mental capacity legislation—particularly in relation to the ability of people to consent to treatment. We will do that whether it is in hospitals, private hospitals, community hospitals, or care homes and in domiciliary care.

**The Chairman:** How effective do you think the monitoring is?

**David Behan:** This is a new responsibility for us. We have taken this on board and if you look at our Annual Report you will see that, from 2010-11 to 2011-12, there was much more take-up of the mental capacity legislation across services. That report flagged up the variability in the degree of knowledge of the mental capacity legislation. The great variability in that knowledge will impact upon the quality of practice, and our monitoring has identified that variability. We made a number of important recommendations to commissioners and providers of care in our Annual Report last year, which said there is more to be done to ensure people understand the legislation.

In my view, this is less about understanding the legislation and more about understanding what good practice is. In CQC, we are of the view that the issue is about what is best practice—particularly for people who might not have capacity. How do you work with people without capacity? How do you work with those people as individuals, but also their families and their carers, who will have a good degree of knowledge and can be of assistance in arriving at decisions?

An overemphasis on the legislation detracts from a debate about what best practice is. We see that through our work. If I am being brutally honest, Chair, my own staff reflects this variability in knowledge. The knowledge that some of our own inspectors have is variable. When they are out inspecting services, how they use that knowledge to inform their assessments and, ultimately, their judgments is a key issue. Rachel’s post is a deliberate part of our strategy to up our game—if I may use the phrase—in relation to mental capacity.

We are busy carrying out a pretty fundamental root-and-branch review of the way that we inspect health and care services. We are building in mental capacity and the practice we would want to see in the way that we are redesigning our methodologies.

In essence, we are asking five questions of all services. Are services safe? Are services effective? Are services caring? Are services responsive and meeting the needs of the people they are there to serve? Fifthly, are those services well led? What is the culture of the organisations?
Our view is that mental capacity and the practice around mental capacity needs to be a feature of all five of those significant questions. As we build our new methodologies, we will ensure that mental capacity is built into the way that we conduct our inspections—whether of hospital services, community healthcare services or, indeed, adult social care services—so that we can give a view about how well people are served by the way those decisions are made about their care and treatment. For those people who are not able to consent, we will assess how they are engaged, i.e. how practitioners go about engaging them and making the appropriate assessments and judgments to support people.

Q198 The Chairman: Your submission states that you would welcome discussion with professional regulators to explore whether it would be appropriate for them to become more active in the regulation of the Mental Capacity Act. What discussions have you had to date with such organisations? How do you ensure that issues do not fall between two stools, as it were?

David Behan: This is a highly appropriate question. We have had this issue about what the interface is between us as a quality regulator and professional regulators—not just on mental capacity, but much more generally. We have a pretty extensive programme of developing memoranda of understanding with our professional regulator colleagues. We have recently signed and completed an MOU with the General Medical Council and, indeed, published some practice guidance, which goes into some quite granular detail in terms of, “If you find this set of circumstances, this is what you should do and this is who you should contact.” This works for both GMC staff and CQC staff. We are beginning to complete this programme of developing memoranda of understanding. A number already exist and we are reviewing those as we change our methodologies to ensure they are built into the way we operate with our professional regulator colleagues. The Department of Health have convened the Mental Capacity Act Steering Group and we are a member of that—as are the professional regulators.

There is also an important dimension to this, Chair, in relation to the emphasis that this is a professional and practice responsibility. Earlier, I referred to an overreliance on lawyers in relation to mental capacity. We have given too much to the lawyers and not enough to what the best professional practice is. I am certainly looking for the professional associations and regulators to take some lead in relation to this to debunk the complexity. I begin too many conversations about mental capacity with people saying, “This is too complicated.” This is essentially about how you engage with people to ascertain their wishes about how they would like to be treated, whether you do that up front, before people lose the ability to consent, or where people are beginning to lose that ability, by working with them.

Without wanting to digress, Chair, I trained to be a social worker in the very early 1970s. One of the key principles of social casework was client self-determination. It was about asking people what they wanted and working with them to work that out. Somehow, in the 1980s and 1990s this stuff has been forgotten and we need to return to it. This is essentially not just about social work colleagues but how clinicians—there are some on your Committee—work with people who are losing capacity, or before that point, and how other professionals working in health and
care can work to support appropriate decision-making about appropriate care and treatment.

**Q199 Baroness Andrews:** It is very interesting to hear you talk about your new inspection regimes in this context, because you say in your evidence you do not inspect against the five principles that underpin the Act. To an extent, they were the principles that expressed a real culture change—and the aspiration of that culture change. I wanted to be clear about this: as you approach your new inspection regime, do you think you can address those principles? Do you think that can in fact bring a culture change? I agree with everything you have said about practice; however, is that going to be part of the methodology?

**David Behan:** I do think that is the case, Baroness Andrews. We literally said—it was a very literal statement—we do not use those five principles. However, we are attempting to judge the quality of a person’s experience in receiving health and care services. We have been quite rightly criticised for having a pretty mechanistic approach to inspection where we have inspected against those key standards. The phrase used was that we have had a tick-box approach to inspection. Some staff would find that judgment a trifle hard. Nevertheless, over the past few years we have had an approach to inspection based on compliance with standards. What we are signalling in our change is that we want to move away from an inspection system that is based on compliance with standards, to one that is much more about the judgment of the quality of people’s experience of services.

The point I was trying to land about practice is that one of the key elements of good professional practice—Robert Francis highlighted this in his own report—is the importance of listening to people and engaging with them. Once you have listened to them, acting on what they have said is important: it is not just about listening; it is about doing something once they have said it. To use different language, it could be described as care that is personalised. It is built around the individual. If you have care that is personalised around individuals—that listens to them and then acts on that—you will promote people’s human rights. The best way to promote people’s human rights is to have personalised care: not to treat everybody the same, but to treat everybody as individuals.

Personalised care should be the model. I do not mean that people get personalised budgets, but that care is personalised. If I live in a care home and I have never eaten cheese, then personalisation is making sure that I do not get cheese sandwiches at teatime. Some of these are quite simple things; they are not great big complicated issues. Our job is to assess whether that care is meeting people’s needs and looking at those kinds of issues. Our question about whether services are caring is essentially designed to get at whether people with capacity or without capacity are receiving care that is personalised, which promotes their human rights.

You do not need a lawyer to do that; you need professionals who know how to assess capacity and who, after having assessed capacity, can then put together care plans that identify how somebody’s care is going to be promoted. If we go into services and we do not see care plans, alarm bells will be ringing, because I will be thinking, “How are you going to promote people’s best interests if you do not have a proper assessment and a good plan in place?”

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Q200 Lord Swinfen: If I heard you correctly, you said that best practice was more important than the Mental Capacity Act. Does best practice always comply with the law or not?

David Behan: I hope I did not say it was “instead of” the Mental Capacity Act.

Lord Swinfen: You did not say “instead of”; you said “more important than”.

David Behan: I was trying to emphasise that practice is more important than lawyers interpreting the law. Effectively, what I was saying was, “Please do not give this issue to the lawyers; give it to the professionals and practitioners to work out how best to do this.” That was the point I was trying to land. If I have done that clumsily, you have my apologies.

Lord Swinfen: Do you think it still complies with the law? I know you are not a lawyer—neither am I—but could you answer as a layman?

David Behan: We are together on that. It is essential that practice complies with the law. However, it is also essential that we treat the law as a framework. My belief is that the mental capacity legislation is a framework within which best practice needs to be demonstrated. It is for professionals to make their judgments and decisions about how they are going to operate within that framework and make decisions that are in the interest of individuals.

Earlier, answering the Chair’s question, I referred to the variability we see. Within that variability, you can see people who understand the legislation and are working within the framework and the principles—to come back to Baroness Andrews’s question. You can see those being delivered. Through our work, we also see situations and cases where we do not think that this is the case—where people are not working within the principles. I have already referred to that very practical example. Looking at a care plan, it is very difficult for us to arrive at a judgment as to whether that care plan is going to deliver services that will meet an individual’s needs and promote their wellbeing if there has not been a proper assessment of somebody’s capacity and capability.

This afternoon, your Lordships are considering the Third Reading of the Care Bill. One of the principles in the Care Bill is to move from what I would argue we have had historically in social care legislation, which is the principle of less eligibility, to a principle that is about promoting people’s wellbeing. This is a seismic shift in the way our legislation is framed. If you can take the Care Bill, when it receives Royal Assent, alongside legislation like the mental capacity legislation, which has that principle of doing no harm and, indeed, promoting people’s wellbeing, you have a double lock on how the law provides a framework within which that best practice should operate.

Q201 Baroness Andrews: My question—it has been covered, but I am going to ask it anyway—is really about this conflation between the problems that we have seen in health and social care in recent years and the lack of good care, which is causing such a challenge and such anxiety to inspection regimes. Within that, there is the particular issue we are facing about the difficulties of implementing the Act and

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assessing capacity, the assumption of incapacity rather than capacity, and so on and so forth—all the things that have been brought up in evidence to us.

To what extent would you say that the failure of the MCA to be implemented properly is a reflection of the wider failure that you say you are addressing in your evidence? We have two sorts of evidence in a way. We have statements from you and others saying, “If you have a good care setting, they understand the principles of approach to a person with incapacity,” and we have other sets of evidence that say, “You can have a residential home that is inspected and meets the test, yet within that there is a particular problem with people with mental incapacity, because whatever is missing—failure to understand or a lack of communication skills—is having a real negative impact on that person.”

The question is about those related issues and how you would help the Committee to interpret and improve on them.

David Behan: This goes back to the question you asked earlier about whether we have shifted the culture; this was also behind your question, Chair.

What our evidence would show—I make this statement quite deliberately—is that there is too much variability in a) people’s understanding of the legislation and b) how that understanding influences their practice. In our last report, we made recommendations to both commissioners and providers of care—the people who run hospitals and care homes—about what they need to do to ensure their staff understand not only what the legislation says, but that they are then able to translate and interpret the legislation as to how it impacts on practice.

Two examples come to mind. I am interested in hospitals and how they get to a do-not-resuscitate decision. How do they get to a nil-by-mouth decision? Who is involved in that decision? How is that decision taken? For people without capacity or with variable capacity, how are relatives engaged in that? In our inspection processes, it is not just about saying, “Tell me how you implement the mental capacity legislation around here.” That is one way to do it, but I am sure if you asked that question what you would get would be, “We do it very well. Here is our adult-centred training programme. Here is the curriculum,” etc.

The real question, however, is not, “Do you run a curriculum for mental capacity?” but, “What does this mean for the way you make decisions around here? How are those decisions made? How does that impact on the quality of people’s experience of services?” In that respect, our role as the regulator is to shine a light on those issues; to mix my metaphors, our role is to hold up a mirror to people and say, “What we found when we visited this service is x, y and z. We think there are some areas for improvement here.”

We are not the answer; we are only part of the answer. The answer must come from the way that commissioners—health and local authorities—commission services and the way that providers take on their responsibility to ensure their staff are aware of the legislation and are able to operate that.
Baroness Andrews: May I ask about training? This is an issue you have raised. It has come to us from many different directions that there needs to be better training in the Act. I take everything you say: the Act is the starting point, not the finishing point. However, you refer to the curriculum and so on; do you think there is a role for improved or more systematic or more generalised training? Do you think that is relevant?

David Behan: Yes, I do. If you look at the turnover we have in care homes and hospitals with healthcare assistants, there is a role for it. Where you have bank and agency staff working in both hospitals and care homes, it is not just that you have this rapid turnover of people; you also have bank and agency people coming in and out of these services. It is absolutely essential that all staff who work in health and care—whether that is working with younger disabled adults or older people—need to understand the legislation.

However, they need to understand it not so they can tick a box to say they understand the legislation; they need to understand it so they know what the practical implications are of working with an 85-year-old who is quite confused because she has dementia. If there is a son and a daughter, one of whom lives in Australia and one of whom lives in Canada, who are the next relatives who are going to be involved and engaged in those decisions? These are not hypothetical positions; these are real situations. 65% of people in all of our acute hospitals are aged over 65; these are occurrences that happen on a regular basis. The average age in a care home is over 85. These should be the default settings of these services, not the exceptions. Our work has shown that we are a long way from this being the default setting in all of our services. That gives the stretch of what more needs to be done.

I have a slight hesitation in talking about training in relation to this. This is probably a personal opinion, rather than something we have found. I hold my hand up; I did this myself in the 1980s. In respect of some of the equalities legislation, I said, “Every member of staff in this area I am responsible for needs to go through equalities training.” We sheep-dipped people through this equalities training and we wondered why it did not make a difference. What I would want to do is exercise a cautionary note about the solution to this being to push everybody through mental capacity training. The issue is more about workshops, so that people can understand what the practical implications of this are. Some of this is on-the-job support for people. It is about using cases to have a review and a conversation with people who are making these decisions so that they are doing it in real time. It is about having senior practitioners and registered managers who can coach staff through making the appropriate decisions, rather than just seeing it as a training programme.

It is much more about development. This is where you begin to get a change in culture—rather than saying, “Let us put every member of staff through mental capacity training; have you done it?” and the aim being to get x number of people through mental capacity training. Actually, the aim is to ensure that, when we make decisions, we are making good decisions based on people’s needs that promote their welfare. That is the cultural shift we are after.

Q202 Baroness McIntosh of Hudnall: I would like to explore that a little bit more. I was very interested in the five principles you have established. The last of
them—it happens to be the last; I am sure that is not a reflection of priorities—was about whether services were well led. This term “culture change” is bandied about an awful lot now. It is the answer to every problem that we find in the delivery of services—whether it is for young people or people without capacity or whatever. It is always, “We need a culture change.” It is very easy to say and very difficult to do, as far as I can see.

Fundamentally, however, there is an issue here, is there not, about leadership? We tend to concentrate on thinking about the people at the bottom of the pecking order and worry about whether they are properly trained, but the way you get culture change is by modelling it and you have to model it all the way through the—I am trying not to use the word, but let us use it anyway—hierarchy of any organisation. It has to start from the people whose responsibility it is to make sure that the culture is appropriate. Beyond what you have already told us, I am wondering what else you can tell us about the role of the regulator in promoting good leadership within these settings—to ensure that we do not just talk about culture change, but that we actually model it and ensure that it gets embedded.

David Behan: If I may say so, you have gone right to the heart of one of the reasons we need to change the way we inspect health and care services. If you look at what we inspected previously, we did not inspect the leadership, governance and culture of organisations. However, what we know—this is not just from Robert Francis’s report; there is a raft of literature on this now from many sectors, not just health and care—is the importance of the relationship between leadership culture and what gets done in organisations. If the signal from the very top of the organisation, from the chairman and chief executive of a board—whether it is an NHS board or a private company board—is, “What matters around here is financial balance and targets,” I am sure that is what will get done. If the signal is, “What matters around here is quality and safety,” I am sure that is also what will get done.

The reality is that—this is what Robert Francis has said and I absolutely agree with him—quality and safety did not receive the attention it required. What happened at Mid Staffs was that it did not get that attention. His report is seminal. The debate about too many recommendations misses the point; his report is the definitive report. It is seminal, because it actually has caused a debate about quality, safety and the importance of listening to people. In my personal view, if I may, Chair, I have not seen the likes of this in my career to date—to be absolutely frank with you.

There is a change in conversation going on and that is supported by research. I am interested in some of the work that people like Jill Maben, Professor of Nursing at King’s College London, have done in relation to this relationship between patient satisfaction and staff satisfaction. It is almost intuitively obvious that, if you do not have high staff satisfaction, you are not going to get high patient satisfaction. How do people who run organisations set the culture of those organisations about valuing staff? This goes back to Kay’s question about supporting their development, not training, to ensure that the important things are being done.

One of the significant changes is that we will look at the culture of leadership. We have asked the King’s Fund to do some work on reviewing all the evidence and literature about what is good leadership in services. That is informing the way we
are developing our new approach to assessing leadership and culture in organisations. We will build that learning into our methodologies.

We are seven inspections into the 18 inspections of hospitals we said we would do before Christmas. These are our new inspections. I have managed to spend some time on two of the inspections, where I have seen how we are changing the way we explore—with the chief executive, chair, non-executive directors and, in foundation trusts, the governors—the leadership and the way they set their culture. How does that governance work? We are reviewing board minutes and what goes to the board. Do these boards meet in private? Do they meet in public? If they meet in private, what then becomes public? How open is the culture? How do they deal with never events? How do they deal with serious untoward incidents? Are these things that are kept within the board or are they analysed and then reported to the board in public session, so it is obvious that people can learn from them? Those are some of the questions we have been asking.

Q203 Baroness McIntosh of Hudnall: I am sorry to interrupt you, but, on that issue, what is the value or efficacy of the Mental Capacity Act specifically in relation to the kind of education you are thinking you might need to do with people? Particularly since you have mentioned board members and non-executives, do you talk to them about the Mental Capacity Act when you are inspecting? Do you ask them to be familiar with it? In what way is the Act a useful tool for you?

David Behan: I did an inspection at Bournemouth last Friday. As we gathered together to review what we had learnt and what we still needed to learn, I asked that three specific conversations went on with key executives within the trust. One was, “What is the policy on nil by mouth?” The second was, “What was their policy on do not resuscitate? How do they apply that?” The third was, “What was their policy in relation to the Mental Capacity Act? How do they know they are delivering it?”

As I say, these are seven of our first 18 inspections. The wave-2 inspections will build this in based on the learning that we extract. Rachel’s post exists specifically to ensure we have this capacity. As part of our preparations for this session, Chair, I have been hearing how Rachel has been engaging with the people who are designing our methodologies to make sure this is hardwired into the way we operate. I do not want to overlabour this, but the reason I talk about nil by mouth and do not resuscitate is that my experience of inspecting services is that, if you ask people, “Do you have a policy on the Equal Opportunities Act, the Health and Safety Act or lifting and handling?” etc., they will say yes and they will give it to you.

The Chairman: You have already made that point. However, Baroness McIntosh was wondering about the non-executive directors. What do you do to inspect that, at board level, non-executive directors are aware of that and their obligations?

David Behan: Chair, my point—not to push back on that—is that we do not have a checklist to work our way through with non-executive directors. The key question we are trying to answer is this: how well run is this place? How do you deal with these things? It is not about running through a checklist.
In answer to both of your specific questions, we have not landed this properly. There was a specific interview between two inspectors and two non-executive directors. They had key lines of enquiry, as they are called, which are the issues that had come out from our analysis, about how those hospitals are run. There was a specific conversation that went on for about an hour and a half, I understand, in Bournemouth, with two non-executive directors. At the same time, similar questions would be asked of the chairman and the chief executive and of the governors in a foundation trust. We come together and say, “This is what we heard here; this is what we heard here; does that triangulate?” As you take a diagonal slice through an organisation, is there consistency in how people talk about this? We will be looking for consistency between what a ward sister is saying and what a non-executive director is saying about the way in which things like mental capacity are taken forward.

The Chairman: We have a lot of business to get through; I wonder if we can perhaps move to Baroness Shephard.

David Behan: I am with you, Chair.

Q204 Baroness Shephard of Northwold: I have a very brief question. You told us you did your training in the early 1970s. You will therefore be familiar with the introduction of the Mental Health Act 1983. There were very clear guidelines—not to say statutory requirements—in that Act for involving all, for example, of a hospital’s hierarchy—I will use the word—including people of the governing body, in what was required by the Act if people were going to be deprived of their liberty. Most people seem to feel that the Act worked quite well. I was one of the very early commissioners. We found that there was good understanding and, if there was not, after a visit one was soon put into place. Why is there such difficulty, do you think, with the implementation of the Mental Capacity Act, comparing the two?

David Behan: That is a big question.

Baroness Shephard of Northwold: I meant it to be brief. I am sorry. It does seem to be quite relevant.

David Behan: No, it is an important question; I do not mean to be dismissive of the question in any way, shape or form.

The 1983 Act was largely based on the 1959 Act, which describes a whole bunch of services and a demography that we have moved past. We are 50 years on from that. The population that is there to be served and the services that are there to meet the population’s needs have changed quite dramatically. That is the answer I would give to what is different. We have more people living into old age, where dementia and issues around capacity are an issue. There are more people with profound disabilities that raise some challenging questions around consent and the ability to consent. The job has become infinitely more complicated over the last 30 years compared with 1983. I do not mean it was easy in 1983; it has become more complicated. That would be the answer I would give you.

Baroness Shephard of Northwold: The answer you have given me is really talking about volume, in a way, rather than complexity. However, I do not want to
hold the Committee up. This is an issue we have explored with other witnesses; that is the thing. I wondered whether you had a view on why one worked and the other seems more difficult. I accept complexity; I accept volume; however, there are also principles, and that is what I was trying to get at. We may get at that later on.

**The Chairman:** Yes. If not, perhaps you could submit something in writing in elaboration to your answer to the question.

**David Behan:** If I am failing in my answers, Chair, I apologise.12

**The Chairman:** It is only the pressure of time. Could we move on?

**Q205 Baroness Barker:** As the regulator of health and social care, you have a unique insight into the way in which this legislation works, which is very important to us. On the issue of variability, a number of the social work organisations have said to us that the Act is not really being used in the way that was intended, i.e. enabling and empowering people without capacity. It is actually being used to substitute safeguarding legislation. They have talked in particular about different professions taking that stance. For you, as the regulator, what do you see as the balance between being seen to take action—and ensure services are safe and so on—and ensuring that professions do implement the enabling ethos of the legislation?

**David Behan:** There has been some defensiveness around a lot of practice. There has been caution about taking risk. That is understandable at times, in the way that where risk is seen to go horribly wrong the debate tends to turn on who is to blame, rather than what learning can be extracted and how services can be improved and developed. That is not to say that there is not an important place for accountability. We often scramble these things in a horrible way. It is defensiveness. As I have already said, the level of knowledge around the legislation is not sufficient. In a sense, there is ignorance as well. This is not necessarily about people doing things wilfully wrong.

However, we do need to balance empowering people. This goes back to the first question. It is about the ambition, which is about empowering. The best way to do that is through personalisation. That is carrying out individual assessments and

12 In response to the generous offer from the Chairman to submit a written elaboration to this answer, I would like to add that he MCA is far wider in its scope than the Mental Health Act, being to do with the holistic welfare of a wide range of people who may lack capacity for some decisions at the time they need to be made. From this standpoint, the MCA has to be understood by many professionals, not only, but of course very importantly, within health and social care. It has taken time for the implications of the MCA to percolate throughout systems, policies and staff development, to become the framework for practice.

We believe that a tipping point is now being reached, where the Act is becoming much better understood, as the foundation for decision-making in difficult situations where professionals must balance someone’s right to autonomy with an understanding of when, and how, a decision can be made for someone who lacks capacity.

Part of embedding and strengthening this within health and social care is that the CQC, as said elsewhere in my evidence, is hard-wiring the MCA into our processes. We are helped in this by the change to our Regulations regarding consent, which now makes explicit the requirement that decisions regarding people lacking capacity to make them at the material time are made in accordance with section 4 of the MCA.

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having individual care plans that are about meeting individual need. That is the best way to ensure there is a human-rights approach to practice. The legislation strikes the legal framework within which that practice can be organised and arranged. That is our view; it is what we are doing in seeking to build this into our inspection methodologies, and it is what we will continue to do. Our teaching to inspectors already emphasises the importance of decision-making within the Act when assessing risk.

Do we need to ensure that people’s wellbeing is safeguarded? Yes, we do. This is why I referred to the Bill that is in this House later this afternoon. It begins by stating that the overriding objective of the system is to promote people’s wellbeing—and that is entirely consistent with this Act.

Q206 Baroness Hollins: You have talked quite a bit about revising your standards. One of your five areas, however, was about whether a service is responsive to people’s needs. I wanted to focus a little bit on people with learning disabilities, who are often thought of as being a separate group, but are actually present in all of the services you inspect. They cannot be seen as a separate group and thought about separately. One of my questions is whether you have considered checking how responsive all services are to the needs of people with learning disabilities—particularly in respect of their capacity.

You have talked about personalisation as if it is more of an attitude than a skill, but there is quite a lot of skill in assessing people’s needs, assessing their capacity and making the kind of adjustments that might be needed in order to be able to assess capacity and for people to be able to make full use of services. One example you have given is about do not resuscitate and things like that, but you could look to see how specifically that or any of these difficult decisions are being applied to people with learning disabilities, who are particularly vulnerable and who are present in every service. I do not know whether you have an answer to that.

David Behan: Andrea will help on this as well, because she will lead the inspections of a number of services that are delivered to people with learning disabilities and will do some joint work with the other two chief inspectors around exactly this—to pick up on Baroness Barker’s point and the point you are also making in relation to this.

However, one of the things that we have more reflected on than actually said overtly is that, if we can get our inspection methodologies right for people who are viewed as being vulnerable by virtue of their circumstances, we can get this right for everybody. From Mencap’s Death by Indifference report and the response that has come through from Sir Jonathan Michael’s enquiry into this, we know that services for people with learning disabilities and acute health needs are not as personalised as they could be. People are not listened to; their families are not engaged. In Death by Indifference, that contributed to people dying, quite frankly.

There is much more that can be done in relation to this. I am sorry, Chair, if I am repeating myself again, but it does come back to personalisation being an attitude and a skill. It is not one or the other. If we are getting those basic assessments right and getting care plans in place, where we are listening to people and engaging their families, there is a greater chance that we will get these things right. This is why
there is an important role in our inspections to assess how well services are meeting the needs of those most vulnerable people and those without capacity to consent. We do look at that now and we will continue to build that into our methodologies.

Andrea, you are going to lead on this work for adult social care.

**Andrea Sutcliffe:** Yes, thank you. Building on what David has just said, we will be taking that overarching framework of five questions in terms of looking at the extent to which services are safe, effective, caring, responsive and well led. This absolutely impacts on services for people with learning disabilities. However, the point you are making about them being present in all the services we are regulating is very well made.

Across the three chief inspectors, the most recent reflection we have had is thinking through learning lessons from what Ofsted do in terms of looking at schools and focusing on what schools judged to be “good” or “outstanding” are doing for the pupils who have the greatest needs. A school does not get to be “outstanding” unless they can demonstrate they are approaching that particular cohort of pupils appropriately.

What we have been reflecting on is that people with learning disabilities or dementia are among our special vulnerable groups. If we looked at all of our services specifically for those people in order to answer these questions, we would have a very good insight into the way services were being delivered for everybody. If they are getting it right for people with learning disabilities, we have a fighting chance that they are getting it right for other people as well.

**Baroness Hollins:** This is very important. There are so many worrying stories: for example, people with learning disabilities not having investigations or treatment and going home, because of a failure to sort out their capacity and use the Mental Capacity Act properly. To me it seems like a very good area to look at, whichever service the person is attending.

**Andrea Sutcliffe:** I would entirely agree with you. It is about taking that whole-person perspective and focusing on what is the most appropriate thing we should be doing to support people, acting in their best interests, which, again, is an important principle for us to be taking forward, and not presuming that people either do or do not have capacity to agree or not to a particular course of action.

David said the Mental Capacity Act gave us a good framework; it ought to be integral to the work that we are doing both in delivering services and, for us, as the regulator and inspector of those services, building on that principle.

**Q207 Lord Swinfen:** Your written submission states that you do not think you require further statutory powers. Can you elaborate on why this is, when you also identify a potential gap in regulation and supervisory bodies, and you make it clear that you do not inspect against the five principles of the Mental Capacity Act?

**David Behan:** What we were saying in relation to this was that the Act itself works. It is a good piece of legislation. To come back to your earlier questions, the issue in order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
that we have identified in our monitoring—this was behind your question as well, Baroness Shephard—is the way in which it is being delivered and supported to be delivered. As I have already indicated, we wish to build this into our new methodologies and give it an important place in our inspecting methodologies.

We do not have a responsibility for assessing the role of local authorities in commissioning decisions that are made. As a regulator, our responsibilities are focused on the provision of care and the quality of that provision. That said, this year we have written to local authorities if we feel our monitoring has exposed whether they have been carrying out their supervisory responsibilities in an appropriate way. Where we have identified that we feel supervisory bodies have not been discharging those responsibilities, we have written to those authorities and asked them to review how they are taking forward those supervisory responsibilities. What we were saying in our evidence to you is that we think the powers we have to monitor the implementation of the mental capacity legislation are sufficient.  

We are going to change the way we inspect hospitals; we will build this in. This is how we intend to move forward.

**Lord Swinfen:** When you write to local authorities, do you get satisfactory responses and do you go and inspect again?

**David Behan:** We do not inspect local authorities.

**Lord Swinfen:** No, I know you do not.

**David Behan:** However, we will go in again and look at whether this is improving. Of course, we have this ongoing responsibility to monitor the implementation of the legislation, which means we will pick this up through our ongoing monitoring. We are due to produce an Annual Report and we will be looking to build this into that.

**Lord Swinfen:** Are your inspections under notice or do you simply turn up?

**David Behan:** The majority of our inspections are unannounced inspections, so we simply turn up. Clearly, they are planned from our point of view, but approximately 97% of our inspections of services are unannounced inspections.

**Q208 Baroness Barker:** The evidence that has been put to us is that DoLS, the deprivation of liberty standards, are not being applied in all cases where they should be. Could you tell us what your role is in the inspection and regulation of DoLS? If we were to envisage a point when those standards were being properly implemented, what would it take to get there?

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13 Information provided subsequently for clarification: In our specific role to monitor the deprivation of liberty safeguards, we have worked closely with ADASS and with local authorities to explore collaboratively their practice in this area. We have surveyed all 153 local authorities and had an excellent return rate of 118, providing helpful information which we plan to expand on during the next year.

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David Behan: Again, our responsibility in relation to DoLS is to monitor the implementation of the legislation as it relates to the deprivation of liberty. We do that through our inspection process. Where we identify that it should be applied—whether that is in people being inappropriately restrained or consent not being sought—we can take action, and in certain circumstances we do take action. Where we take action, we will take action under the Health and Social Care Act, which is where our regulatory powers come from, as distinct from our monitoring powers under the mental capacity legislation.

What we have put in our Annual Report, Baroness Barker, is where we have taken the action and what we have done. However, one of the things I was saying at the beginning of this session was that there is more that we can do. Some of the variability in services we talked about we also have in the way we take this forward. One of Rachel’s roles is to work with us so that we can grow our capacity and capability within the organisation to ensure that we are doing both our monitoring and our regulatory activity in an appropriate way.

I am not for one minute saying that we have this sorted. There is more for us to do, but it comes back to Baroness McIntosh’s question: we need to model what best practice is in the way we conduct ourselves. When Robert Francis attended our board meeting in the earlier part of the summer, he made this point about the importance of the regulator modelling what the appropriate behaviour is. We cannot talk about variability in understanding the Mental Capacity Act and then have variability in our own understanding. It strikes me that we need to be better than that—and that is what Rachel’s role is for and about.

Q209 The Chairman: Can I ask a question of Rachel Griffiths? Do you have experience of implementation of the Act? The General Medical Council’s written evidence states that when the Act was implemented, regional implementation advisers were an effective vehicle for assisting systems and professionals in each health authority in England and local health boards in Wales. Do you consider that it would assist to reintroduce such advisers to help secure the change of culture we have been discussing?

Rachel Griffiths: It is possible. Those regional leads were immensely useful and very influential. However, we have moved on somewhat. For example, I note that all clinical commissioning groups have to have a Mental Capacity Act named lead in order to be instituted. I was very pleased to see that, as you can imagine.

I would be sorry to see those roles not taken advantage of within local health economies to improve the Mental Capacity Act—both highlighting and implementation. As well as regional leads in those early days post-2007, local authorities all had Mental Capacity Act named leads who worked under the umbrella of the Department of Health. Although some of them still have those, quite a lot have either subsumed it into adult safeguarding or have got rid of it altogether. Where there are Mental Capacity Act leads, the understanding is stronger. For example, I know that hospitals with MCA leads do demonstrate more of an understanding of appropriate practice.

The Chairman: Thank you very much for your evidence. It has been very helpful.

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The Chairman: Good morning. Welcome to this session. You will be aware that the proceedings are webcast, and also you will have the opportunity to alter the transcript if there are any obvious errors. Could I start off by asking you—and you can tell us by reference to examples in practice—what you see as the role of families and carers in decision-making for someone who may lack capacity? Could I start with Moira Fraser?

Moira Fraser: Morning. Carers have a really key role in decision-making where someone lacks capacity or may have fluctuating capacity. They are the people who are most likely to know about that person's likes or dislikes. They are likely to know about what has worked in the past and what has not. They are likely to be able to communicate best with the person. Often, if someone is distressed, they are most likely to be able to know what will calm the person down and enable them to make
as much of that decision themselves as possible. So carers have a really key role to play in this whole process.

There are examples that show how important that is. We have an example of a young man with autism who was asked about his care provision. He was asked whether his care provision had ever fallen down. He understood that to mean “had he ever fallen down”, so he said “no”, but of course it had; his care provision had fallen apart and broken down quite frequently. His carers were in the room and tried to put that straight, but unfortunately they felt that they were not listened to because so much emphasis was placed on what he said as opposed to their view. That shows the kind of miscommunication and misunderstanding that can happen if you do not know the person whom you are trying to support to make the decision.

The Chairman: Ms Holzhausen, do you have any practical examples from your own charges’ position?

Emily Holzhausen: Indeed we do. I just wanted to say that we are using the term “carer”, which is a term in legislation, but of course it largely means family and friends—mothers, brothers, sisters, wives, husbands, partners, sons, daughters and close friends. Of course, quite often people care out of a sense of love and duty towards family members. That is one of the primary reasons why they have a very valuable role to play in best-interests decisions for the person being cared for. That would particularly be the case where somebody might be displaying slightly bizarre behaviour, and that is able to be put into context. Someone might like or dislike change, and that might be a fundamental issue. For example, certainly I know of a number of examples where people have cared very much about their appearance and there have been particular likes and dislikes. An example might be a woman who had never worn trousers in her life and had always been incredibly well turned out. However, because of dementia, she was not able to make her own decisions but the family still felt it was very important for her to be dressed in a way that she felt was right for her, even though that required a little bit more time, care and attention. So there are issues like that where people feel that they have a very important role in maintaining the dignity of the person being cared for.

Oi Mei Li: I have several examples of how the family role can help. First, in assessing capacity, families are best placed to know what people’s routines are. I specifically work with families of people with learning disabilities. Sometimes those routines—those likes and dislikes—are really important to somebody. For instance, we have an example of someone who was trying to ask a young man with learning disabilities a question. He was watching his favourite TV programme, and he does not like to be

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disturbed while he is watching that. If you asked him a question then, he would probably display signs of challenging behaviour and he might be assessed as not having the capacity to make a decision. But a family carer knows about the routines and knows that, if you want to ask him a question while he is a watching TV programme, it is better to ask him later on as you may have a better period of engagement with him. They are more likely to know the communication needs of the individual.

Also, looking at capacity and best-interests decisions, family carers have a role in helping in individual practice-making decisions, especially from childhood to adulthood. Even asking someone, “What would you like to wear today?” and asking for their opinions helps to give them practice in making decisions of their own. Also, families can point professionals out to documentation such as care plans or health plans, which might help in assessing capacity or in making a best-interests decision.

Q127 Baroness Browning: Could I just pick up on something that Moira Fraser said when she was giving us an example of the parents of the boy who were not listened to? I declare an interest. I describe myself as a “named carer” because it is my name on the care plan and I countersign the care plan for an adult son. The term “named carer” seems to have been dropped by social services and medical practitioners, and there seems to be a sort of pushback and resistance to recognising that family members can provide that information. Are you finding that that dropping of the term, which was used quite frequently at one time, means that there is no specific person whom they feel they have to consult?

Moira Fraser: The term “named carer” is not commonly in use now.

Baroness Browning: No, I know it is a bit old-fashioned.

Moira Fraser: It will very much depend on practice. For example, where a GP practice was working with a person with a disability who lacks capacity or in another situation, we would encourage them to identify the carers, to support the carers and to help them to understand what is there for them in terms of their own rights but also to involve them in decision-making. That is an ongoing issue about awareness-raising among health professionals and social care professionals about the importance of carers. Without understanding the crucial role that the carer plays in decision-making—and not only in decision-making but in the whole life of the person concerned, as well as the life of their family, and the role that they play in the provision of care—then we are missing out a crucial part of the equation. It is a constant struggle to raise awareness of the importance of carers.

Confusion around the term “carer” is often in terms of whether it means a friend or family member or whether it means a paid care worker. We use the two terms differently. When we use “carer”, we mean an unpaid member of the family or a friend, and we use “care worker” in order to try to differentiate between the two, because there is a lot of confusion.

Baroness Andrews: Can I follow that on and slightly broaden it out? What impact has the Act had on the way that you work, on your organisations and on your own sense of responsibility? I ask that not just in relation to this question but in relation

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Carer’s Trust, Carers UK and National Family Carer Network – Oral evidence (QQ 126 – 138)

to other questions that we will be going through. Clearly, you have already raised one point in relation to the business of promoting the interests of carers as a whole.

**Emily Holzhausen**: Carers UK provides a lot of information and advice. Interestingly, we feel very much that the Mental Capacity Act applies to families. They are supposed to know what is in the code of practice, but actually it is an incredibly high bar for families to fulfil the Act if you think about ordinary people having to do these things. We developed some information resources with carers, building from the bottom up what they need to know and how it will affect them—everything about dealing with people with mental ill health, learning disabilities and dementia through a whole range of ages and circumstances. It is one of our most popular leaflets. It flies off the shelf. That just goes to show how critical this is.

Professionals have to abide by the code, and occasionally there are attitudinal issues that parents bump up against—certainly the parents of sons and daughters with learning disabilities. There are attitudinal issues around mental health where carers are not involved. That is a real issue and that is where I think it is really important to overlay the Mental Health Act with the Mental Capacity Act. We could actually give families more rights by just looking at the overlay of the two, but not necessarily by changing anything.

With regard to the Mental Capacity Act, I was thinking about how we advise the carers of people with mental illness. Quite often they are blocked because of confidentiality. The family cannot always make a best-interests decision if they do not have all the information to hand—it may be in the hands of the professionals and not in the hands of the carers. Therefore, they are not equipped and empowered to make the decision. For us, the Mental Capacity Act has been hugely important in helping people to understand what they often make as day-to-day decisions, but it also strengthens their hand in being involved in decisions if they need to be.

I am sure that we will come on later to the legal structures around the Court of Protection. I know that my colleagues will have more to input into that, so perhaps I will leave that one for later. However, we see our role as absolutely vital in helping people to understand how the Act can be used as a tool for improving care and improving the way that care is managed within the home, or indeed in residential care. There is still a right to be consulted; somebody may not have direct care for a person but they may be acting in their best interests, and that is critically important.

**The Chairman**: Can we just move on now to the next question?

**Q128 Baroness McIntosh of Hudnall**: Well, I think the question I was going to ask has been partly answered by what has just been said. You clearly regard the Mental Capacity Act as extremely important as far as the ability of informal or family carers are concerned, but do you think that in itself the Act is clear about what is expected of people who are caring in those circumstances, as opposed to professional care workers? Do you find that, in interpreting the Act, as you have just described, for the benefit of the people who take your leaflet, you are able to interpret it fairly straightforwardly, or do you have to work quite hard to get out of it what you think they need?
Emily Holzhausen: Perhaps I may briefly answer that and then hand over to my colleagues. There is a lot of complexity in the Act but there is a lot of commonsense grounding in it in the five principles. Our leaflet is fairly top-line. There is another leaflet which is 40 pages long. It is very helpful but, equally, very dense. So it really depends on the family’s level of engagement as to how much you need to tell somebody.

As a point of principle, and with reference to when the Mental Capacity Act was going through Parliament, there is a different level of onus on families. Professionals have to abide by the Mental Capacity Act, but expecting families to understand the details of the Act is to place on them a very high level of responsibility.

Baroness McIntosh of Hudnall: But there are compliance issues that apply to everybody who has responsibility for somebody who lacks capacity, whether permanently or occasionally.

Emily Holzhausen: Absolutely. I would say that family members’ level of awareness of the Mental Capacity Act is not huge. It is not great; nor are they necessarily helped to understand it. If your husband has a stroke, you are not necessarily told, “Oh, you need to know the principles of the Mental Capacity Act”. People are taken through parts of it at different times with professionals but there are some good examples of the Carers Trust network that delivers services as well.

Moira Fraser: Carers Trust’s network includes carers’ centres and schemes to provide, among other things, respite care, including care workers. Those care workers are all familiar with the Mental Capacity Act and use it on a daily basis. Our carer centres provide support to carers in terms of finding their way around what this means for them in practice. Usually, that happens only when a third party is involved. So, on a day-to-day basis, carers often do not realise they are carers, let alone that there are such things as the Mental Capacity Act and that there is something that they should be doing to comply with it. It just does not happen. When it happens is when there is a decision to be made, and then suddenly they are faced with the fact that there is a process to be gone through. Or it might happen when someone begins to lose capacity, particularly with dementia, when their financial affairs need to be taken care of. That usually happens far too late in the process.

When our workers work with a family, they tend to use the five principles as a basis. Those are very easy to understand and carers do understand them. The complexities of the Act are things which people only really get into when there is a decision to be made and they are brought to their attention.

Q129 Baroness McIntosh of Hudnall: I am sorry but can I just probe that a little bit more? When those situations arise and there are issues of compliance which need to be unpacked, in your view does the Act, as it is currently drafted and understood, serve the purpose that it was designed to serve?

Moira Fraser: Generally I would say yes.

Emily Holzhausen: On the whole.
Moira Fraser: There are issues when families say that they feel that professionals pick and choose when to involve them. Often they feel that, if they disagree with the decision being made, they are excluded, or it is deemed that they are not acting in the best interests of the person whom they care for, which they often find quite insulting. When they just disagree, that does not mean to say that they do not wish to act in the person’s best interests.

So there is certainly a question around the extent to which carers are involved in decision-making. That is partly what the Act is there to do: it is there to resolve those kinds of conflicts. But if you do not have the information at your fingertips, you are not feeling particularly empowered and it is quite difficult to fight your way into that decision. That is often what carers report—having to fight their way in. On the other hand, they are being asked to make decisions which are based on a poor interpretation of the Act. Often, professionals do not understand the Act and they give an interpretation to carers which is wrong, and that, of course, then becomes problematic.

The Chairman: Oi Mei Li, do you agree with what has been said?

Oi Mei Li: Yes, I totally concur with what Emily and Moira have been saying. I would say that the code is quite clear that the Act applies to family carers, but in practice there are real problems in implementing it. Sometimes the role can be quite unclear. For instance, in the CQC report on the use of the Mental Capacity Act, lots of family carers reported that clinicians, police and mental health experts expected family carers to have a level of knowledge that they just did not have. They do not have that information. The confidential inquiry said that there is a lack of adherence to the Mental Capacity Act and that family carers were not involved as much as they should have been. The same applies to Winterbourne—carers were not involved even when there was deprivation of liberties. People were making complaints but those just were not getting through and they were not being listened to.

In regard to the provision of information, I again totally echo what Moira and Emily said. We have produced a resource guide for family carers on the Mental Capacity Act and it includes a DVD with stories of family carers. It is one thing to try to look through the code of practice but it is another thing to hear how it applies to you in practice. There is a great barrier to family carers in receiving information. Charities such as ours can give advice. We can give out workbooks and we even hold workshops. We ran regional workshops around the country so that family carers had a chance to meet and ask questions in a safe space. But we are not—I am speaking for myself really—qualified to give individual advice. We can give information on the process and we can signpost people to other areas, but we are not qualified to give individual advice. We are finding that helplines are suffering from funding cuts. The national mediation service no longer exists, and citizens advice bureaux around the country are disappearing. If a CAB office opens at nine o’clock, you will find family carers queuing hours beforehand just to get some advice. Then of course you have got legal aid being cut. So on lots of different levels it is very difficult for families to get advice and support.

The Chairman: I think question 3 has already been answered, so we will move on to question 4, Lord Swinfen. I am conscious of the time. We have only another half hour to go.
In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.

**Q130 Lord Swinfen:** Are the provisions on the general defence effective in protecting carers in their day-to-day care of individuals? Are carers equipped to make assessments of capacity and best interests, which are required as part of the general defence?

**Moira Fraser:** Shall I give that a go? Carers would have no understanding, generally, of the general defence. But I would say, in general, yes, it is, providing that someone is acting in what one would commonly regard as the best interests of the person concerned, with regard to their health, well-being and wishes. Yes, I have had no reports of that being an issue.

In terms of carers’ assessment of the capacity of the person they care for, your average carer would have no conception of any formal way of doing that. A day-to-day example: your wife has dementia, you need to take her to the doctor’s and it is raining outside. She needs to put her coat on. She may not want to put her coat on, but you are trying to get her to put her coat on. so you may need to hold her to get her to put her coat on. You try to do that, and she really objects, and you think, “I might hurt her. Okay, maybe we’ll just forgo the coat.” Or paying for small amounts of shopping, taking some money from someone’s purse to pay for the groceries—those are the kind of decisions that that carer makes on a day-to-day basis. A carer does not sit and say, “I need to assess my wife’s capacity today in order to decide whether this decision must be made.” They just get on with the day-to-day business of looking after someone.

**Lord Swinfen:** Do you not think that husbands and wives are continuously thinking of their spouses’ capacity, particularly if they are not well?

**Emily Holzhausen:** Indeed.

**Lord Swinfen:** I am speaking as someone whose wife had a stroke some years ago. I am glad to say that she was not badly damaged—she is now 100%.

**Emily Holzhausen:** It is part and parcel of daily life, and they are day-to-day decisions that people make within families and within relationships. Every relationship is also slightly different, and it will also depend on what the relationship was like beforehand as to which decisions somebody might make anyway for somebody with capacity—where we delegate within a relationship, perhaps. Formally, as Moira said, people do not do a proper assessment, but they build up over time some understanding of capacity. For example, let us say around dementia, certainly families can definitely do with some help and training on what dementia is, when people start to have challenging behaviour, and communication difficulties. Certainly families could really do with specialist knowledge there of how to facilitate that, but I am afraid that we do not put the investment into families that we do into professionals. Yet we expect families to do the same job as professionals, if not a better one.
Baroness Shephard of Northwold: Very briefly there, when people have conditions like dementia or, say, Parkinson’s or whatever it is, there are other organisations—there is a Parkinson’s association—to which people may well turn for help. It just occurs to me that you would not need to reinvent the wheel if you were able to direct people to those organisations.

Emily Holzhausen: And indeed we would.

Baroness Shephard of Northwold: And of course you would.

Emily Holzhausen: Yes, of course we would, because they are the experts.

Q131 Baroness Barker: One of the big changes of the Mental Capacity Act was the change to powers of attorney, the introduction of LPAs and welfare finance. We have heard information about the uptake of those. Do you think that they have made a big difference to carers and do you think that carers have sufficient support from different memory clinics, for example, as well as formally from the Office of the Public Guardian to really make those powers of attorney work in the way that was envisaged?

Oi Mei Li: I do not think family carers know enough about lasting powers of attorney. I can see where they could be very useful. For instance, people with Down’s syndrome quite often have good capacity in their early years and are more likely to have early onset dementia in their 30s and 40s, and it would be really useful for families to know about setting up lasting powers of attorney beforehand; it is much more expensive later on. The main place that we hear family carers finding out about lasting powers of attorney is through solicitors, but sometimes—we found this when we were compiling the information for the resource guide—families are given a little bit misleading information about the powers that they can have under the lasting power of attorney. They are told, “If you want to be involved in decision-making and be the person who can make decisions when your son or daughter needs healthcare, needs to change homes or whatever, then you need to set up a lasting power of attorney.” What they do not understand and do not appreciate is that they are only part of the decision-making process; they are not necessarily the decision-maker. In those instances, there is generally a lack of good information, and that option is not always discussed when it could be.

Baroness Barker: Many of the examples you have given are of people acting as deputies. Do you think there is enough information about that?

Emily Holzhausen: No. Also, on lasting powers of attorney, the finance ones are more common than the welfare ones, probably because of the enduring power of attorney that came before. Quite often, people come too late. Personally, I do not think people have enough information about the deputy provisions. It is quite costly. If you have ever been on to the Office of the Public Guardian website, just look at the different options and things. We are asking for quite a high level of knowledge of administration to be able to get through all of that. I do not know how you would change it necessarily, but powers of attorney have always involved a lot of administration for families. We and other organisations get calls about where people are worried about a specific big decision that they might be making under a power of administration.
attorney and are worried if that would be compliant or not under the rules. That is where, for example, the Alzheimer’s Society gets some very specific questions.

**Moira Fraser**: I think another issue about LPAs is the length of time it takes to achieve one. We had an example of someone whose grandmother went into residential care and tried to get LPA arranged; it took six months, and the grandmother had died by the time it was arranged.

People need to be encouraged to consider LPAs in the same way as people consider wills. We all might need it; we should all do it and have that discussion before it becomes an issue of stigma and of worrying about losing capacity. When people have a diagnosis of dementia, they then perhaps do not want to think about the fact that they are about to lose capacity. It is much better to do it early on.

**Q132 Lord Faulks**: Occasionally, of course, there can be poor or even abusive care, or decisions which classify in the same way. Do you think the Act as it is provides an effective framework to deal with these situations? If not, do you think that there ought to be changes in the Act? What sort of changes?

**Emily Holzhausen**: I think the Act does deal with deliberately abusive care. Of course there is criminal law preceding that anyway, but I think the Mental Capacity Act firms that up. Where there is poor care, I would like to see really, really good read-across to support for the family. As I said, we do not send a nurse straight in to do care without training first, nor indeed a healthcare assistant, but we expect families to take on this role, which is effectively the same as a professional. I have seen instances of poor care—including coming through the courts, certainly—of where the family has not been given the right kind of support. Very often, people will refuse support because it is not right for them or the person that they care for. Before the judgment of poor care is made, simply on the basis of that, I would like to see strong read-across to community care legislation and carers’ assessments and training and support.

**Baroness Hollins**: Could I just ask a quick supplementary to that? This question is about family carers, but what if the poor care is by unskilled paid carers? Does the Mental Capacity Act help there at all?

**Moira Fraser**: It should, yes.

**Emily Holzhausen**: I think it does. Where we have problems in the current system is the structural problems through the lack of training, the contractual arrangements, the commissioning arrangements and the way that services are organised. Really, actually, perhaps we should be using the Mental Capacity Act more in that circumstance.

**Q133 Baroness Shephard of Northwold**: This question has been touched on, I think, already. Would you say that carers were aware of their rights to be consulted when decisions are being made by professionals and clinicians? That has been mentioned, and I was very struck by something one of you said, which was “Carers don’t always realise they’re carers”. Do you think, in addition to all the other things that they have to learn, they know that they ought to be consulted?

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Moira Fraser: No. Generally, they do not, unless they have reason to come into contact with a significant decision that needs to be made. We have an example of someone with a son with Down’s syndrome who was admitted to hospital and was in hospital for 110 days, and they were never consulted on these decisions. There was no reference made to best-interests decision-making. One doctor said to her that he was “drip-feeding” her information as he did not want her to look it up on the internet, and that in no way was empowering her to help make decisions. Carers often feel that professionals pick and choose when to involve them and when not to involve them.

Carers often feel that they should be involved, but they are dependent on the professional enabling that and saying, “Actually, you have the right to be involved in coming to this decision”, otherwise they feel the need to fight their way in. Or they can feel pushed into things very quickly, because the professional suddenly realises that they have to involve someone. The carer has not been prepared for that and does not necessarily understand the requirements upon them or the complexities of the Act, and feels pushed into making a decision quickly. Perhaps preparations could have been laid for that a lot earlier, and they would have been able to weigh up the options and consider things a lot more carefully.

The Chairman: Do both of you agree with that?

Oi Mei Li: I would agree and say that families are more likely to be consulted in social care decisions, we find, but less likely with medical decisions. Family carers would feel that, probably, medical professionals know best.

Emily Holzhausen: The National Carer Family Network have got a whole programme of work around trying to empower people to understand that they can make these decisions, and all of our organisations have experience of where, if you have cared for quite a few years, you tend to learn it. It comes, but it takes a long time, and people say they have to fight like that.

Going back to an earlier point, it was very interesting looking at this and thinking about this in relation to the Mental Health Act. Maybe somebody like Rethink has already done an overlay of the two, where families are consistently excluded from decisions and yet quite often have the care of a person who might have fluctuating capacity or different levels of capacity.

Baroness Shephard of Northwold: Very briefly, should professionals be better trained in realising these important principles?

Moira Fraser: Absolutely.

Oi Mei Li: Yes.

Emily Holzhausen: Definitely. They not only need to be trained in these important principles; they need to understand more about the role of family in providing care, and understand the impact of their decision-making on the carer and the family’s life. What seems to work for them as a professional and works for them as the person

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lacking capacity might be an absolute disaster for the family in managing care—someone having to give up work, or someone being placed hundreds of miles away from close networks. There is an understanding that once the professional is taken out of that it is actually the family that manages that day to day—or it is your son and daughter and you love them and you want to know what is going on, so it is critically important.

Q134 Baroness Browning: Are there tensions between the involvement of carers in decision-making and the aims of autonomy? Do you have any examples of that?

Moira Fraser: There can be, and that is one of the points of the Act—to help to make those decisions. It can go both ways. It can be professionals who are being cautious or it can be the family who is being cautious about the autonomy of the person concerned. Sometimes, for example, you get a family who feel that they would like someone to stay at home for longer. The professionals feel that that is no longer realistic. They feel that the person’s health may well be compromised, and they would like to make the decision for the person to go into residential care. Or it can happen the other way round. There is an example from a Sunderland care centre which was working with a family whose son has learning disabilities and does not use verbal communication very much but can communicate using a computer. He is vice-chair of his local self-advocacy group. He wanted to take on his own tenancy of a flat. The social worker deemed that he lacked capacity to make that decision but his family felt that if you explained to him that he would need to pay his rent on time, how much it would cost, that he would need to keep his house clean, not make too much noise and not bother his neighbours, then he would understand that and would be able to do it. That is the tension. The social worker felt that he did not have capacity and his family did. He wanted his own tenancy but my understanding is that that did not happen.

So yes, there are tensions, but a decision needs to be made and that is the point of the best-interests decision-making process.

Baroness Browning: Can I just follow that up and float something past you? It is this. When family members are involved in really important decisions about where somebody is going to live, perhaps moving them out of the parental home and really big issues such as that, do you think that the professionals—the clinicians, the social workers and so on—sometimes have difficulty in handling and dealing with the emotions of the family member? I often think that that is the case with mothers—hands up. When you have to be involved with something really important like that, it is very difficult to keep you emotions under control. I do wonder whether, in return, professionals find it very difficult dealing with emotional mothers and other carers. Part of their training should be to understand that, of course, mothers are going to be emotional—it is a big decision. That in itself makes them push away the close relatives in terms of critical family decisions.

Moira Fraser: You are absolutely right. It is about training. We have a project called Triangle of Care, which is about involving professionals, carers and service users, particularly in acute mental health settings, but we are expanding that to work in dementia, and it concerns exactly that point. Professionals can have a tendency—not in all cases but particularly in mental health—to see the person in front of them who In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
uses the health service and to see no one else, and they do not acknowledge the fact that everyone else is crucially important to that care being successful. If you do not involve carers and families, you drastically reduce the likelihood of that person’s recovery being successful. There are ways to involve carers which are not threatening but are positive and productive and which will help you in your job. But you need to address that and not think that it is someone else’s job or be frightened of it. Yes, sometimes people are emotional; that is true. So be it, but providing people with the opportunity to participate and giving them adequate information all helps that situation to have the best possible outcome.

Oi Mei Li: I do think that family carers need to be supported, especially during periods of transition. Transition is not just at age 14; it applies to when some adults move home and so on. I think it would be really helpful if information about the Mental Capacity Act could be given to the families of people with learning disabilities, or any family carers, but specifically at age 14. If that was embedded in part of the person-centred planning or in the care programme approach, and possibly if provision was made in the Care Bill so that it was a duty on the CCGs and local authorities to provide it, I think it would help enormously not only through that transition time but through any period of decision-making henceforth.

It is really difficult for family carers. Families of children with learning disabilities are initially asked about every single decision—they are the decision-maker when the person in question is a child—and then all of a sudden the person reaches adulthood and goes on to adult services. They are asked, “What are you doing here? Why are you still waiting to be consulted?” It is a complete culture shock and it has an enormous emotional impact on family carers. That is the start of the problems of conflict. If that role can be supported early enough, I think that people can start to think about how they can be more involved in decision-making with the professionals and how they can include decision-making in part of the person-centred planning and so on, so that it is in all areas of life.

Baroness Shephard of Northwold: I have a brief question. Are you saying that when the person who lacks capacity is in an educational setting—if they are—that might be a good time to start involving parents in all of this? That is a good idea. I do not know whether it happens but it is a terrifically good idea, and it would be relatively simple to do in an educational setting if the person concerned was within that sort of setting, although of course they might not be.

Oi Mei Li: Yes, I think so.

Q135 Baroness Andrews: I think it was you, Moira, who began to talk about the business of people disagreeing with decisions and the really difficult situations that arise from that. The Act obviously puts quite a lot of emphasis on the need for, and the right of, families to challenge those decisions. Do you think that the Act is sufficient in that respect? Do you think that there is enough ability there?

Moira Fraser: I think that carers find it difficult to challenge decisions. There is an example of a family where the daughter has Rett syndrome. The family had to get deputyship put in place because the local authority disagreed with how the family were making decisions. They had to prove that the local authority was not correct in
its assumptions. That took a long time and was difficult. From my reading of it, they seemed to be a very empowered family with access to resource to pay for and understand the process. Not everyone is going to be able to do that very easily. Carers are dependent on professionals telling them what they can and cannot do unless they have access to an organisation such as a Carers Trust network partner or another organisation which can explain to them their rights and how they can go about feeding into that decision or making alternative representations. It is not easy at all unless they are given the right information.

Baroness Andrews: In your very helpful guidance, you spell out very clearly and very practically some of the things that people can do. Do you find that it is being used? Do you have the evidence? Are you being drawn in as an organisation to do some of this work and to take up these cases?

Moira Fraser: Our local partners regularly get involved in supporting people in terms of challenging decisions and applying for lasting powers of attorney and so on. This is not a service that we get paid for or a service that is usually commissioned. It is something that we do as part of the information and advice that we provide to carers in the community. It is sometimes a specialist issue that people need support on. Coming on to the role IMCAs, I think that carers having access to an IMCA would be incredibly helpful if they needed it.

Q136 Baroness Hollins: IMCAs are not usually provided where there is a family member or friend. So the question is: should the statutory provision be extended to include circumstances where a family member or carer is available, and would carers find it beneficial?

Emily Holzhausen: Definitely. We would firmly agree, in particular perhaps where two or more members of the family do not necessarily agree. Certainly there have been cases where carers feel very hard-pressed and at the end of their tether. That is where having an IMCA can help the process. I might add that families who quite often challenge local authorities are then seen as difficult families. As Baroness Browning said, because emotion is tied up with this, it is not a straightforward discussion.

Baroness Hollins: Can I ask you a bit more about that? I am also a family carer. Emotions are one thing, but being assertive as a carer can also lead to difficult ongoing relationships. Is that your experience? Would an IMCA help in that circumstance to enable a person to get a service, because sometimes services seem to be withdrawn from families and carers who are assertive?

Emily Holzhausen: Very briefly, I think that an IMCA would help that situation for certain families, along with other mediation mechanisms and a good working knowledge of all these Acts and how they are supposed to work in concert. Our hope is that the Care Bill, currently passing through your House, will help facilitate this process. There are processes within it that should help underpin the practices of the Mental Capacity Act, including involvement with carers and family members.

Moira Fraser: Certainly there can be disagreement within families on how to deal with the situation. I could give an example of where a decision was made with the
agreement of family members, but those family members were not the ones carrying out the primary caring role, and the primary carer disagreed with the decision. So in that kind of situation, again, the best-interests procedure should take place. However, it depends on how vocal each member of the family is and what support they feel they have. There needs to be a way of supporting carers. The implications of this decision will be huge on them and their lives. They have as much right to a life of their own as the person who lacks capacity. It is not always straightforward; families do not always agree on the best way forward.

Baroness Barker: The point that I was trying to make was about the difference between advocacy and mediation. We are pressed for time now, but if you could give us any examples of mediation services that work well, that would be helpful.

Emily Holzhausen: I think that we will have to provide supplementary answers.

Oi Mei Li: IMCAs have a really important role in representing the individual. I do not have a view on whether it has to be the IMCA role that is extended or another advocacy-type role, but certainly if the person was provided by the same sort of service that provides IMCAs, that would be really useful, because they would have the knowledge. The Foundation for People with Learning Disabilities did a piece of research on best interests that found that when IMCAs are used, there are more complaints and more challenges, because they understand the processes and know what should be happening and when things are not being followed through. That would be enormously helpful for families.

On mediation, we would definitely support it, perhaps at a more local level, so that families who have a challenge do not have to go straight to the Court of Protection, which is really inaccessible for families, certainly financially. The process of sitting before a judge is also so intimidating and daunting. You are challenging the statutory powers. If there was a provision for a mediation service at a more local level, it would be really welcome.

Q137 Lord Turnberg: My question is about the Court of Protection, but your earlier responses provoke me into asking you another one. How does someone who is looking after someone suddenly realise that they are a carer and want to get into the system? How do they come to know of the existence of your organisations? If they go to their GP, do the GPs know about your organisation and refer them? How does someone get into it?

Moira Fraser: That is a long conversation. Yes, GPs should and sometimes do. Both ourselves and Carers UK have a strong relationship with the Royal College of General Practitioners and we do a lot of work on this issue, funded by the Department of Health. That is the ideal situation: the GP recognises that someone is a carer and refers them to local support and the range of services that might be available, including breaks, for example.

However, all too often that does not happen. Our experience is that often someone only realises they are a carer at the point of crisis—often at the point of hospital admission or the point when they are unable to carry on. Obviously, we would like support to be available much earlier. Part of the problem is poor understanding of the role of carers in society as a whole: if there were more general awareness of the

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role of carers, people might not feel so reticent about coming forward and saying, “Yes, I care for someone and that is an important role” and seeking the support that is often available. We know that many thousands of carers do not identify themselves.

**Lord Turnberg:** Is the Court of Protection accessible and effective as a way of resolving disputes? Should there be some sort of less formal dispute resolution system before you get to the Court of Protection?

**Emily Holzhausen:** I think that that would be incredibly helpful. As Oi Mei Li also said, it is expensive. With the amount of time it takes, the legal complexity of the different stages and people not necessarily knowing that appeals can be prioritised and escalated, it really is an area of specialism, apart from the fact that it is incredibly daunting. So, dispute resolution fits in very well with the idea of mediation. Dispute resolution should be as close to the source as possible and quickly resolved. It is best for everyone involved.

**Lord Turnberg:** Is it happening?

**Emily Holzhausen:** I would say, certainly not always. As an example, one of the first cases taken under the Human Rights Act was by the parents of two very severely disabled young women when there was a decision around moving and handling. The family had got into a situation where, because they had been very assertive and challenging, they were labelled as difficult. The girls had to have a legal advocate appointed. It was the first decision under the Human Rights Act—the parents wanted them to be moved by people and not by hoists, because the girls did not like hoists. It was a very good example of where, if people had applied a little dispute resolution and common sense to a situation with very little communication, perhaps that family would not have had to spend two and a half years with the girls going through that process—it may not have been as long as two and a half years, but certainly all the way to the Court of Appeal. It is a very difficult, stressful and painful process. The Court of Protection is not like that, but it is an example of where we need to get dispute resolution sorted.

**Q138 Lord Faulks:** I have one point about the Court of Protection. If you apply to the Court of Protection, are there guidelines suggesting that, “Before you reach us, you should have some sort of informal mediation”? That is the case in other parts of the jurisdiction—it becomes almost a prerequisite that you have exhausted those sorts of techniques before you get to the court.

**Moira Fraser:** The answer to that is that I do not know. I know that our services tell us that they feel it is a sledgehammer approach for comparatively small amounts of money. For example, someone told me that they needed access to less than £5,000 for essential repairs to their mother’s house; they had to go to the Court of Protection for it and it took for ever. They are funding the repairs out of their own resources in the mean time. There must be an easier way of achieving these comparatively small steps forward in decision-making.

**Emily Holzhausen:** Can we come back with advice on that? I would like to get a wider range of recommendations from my colleagues.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
**Lord Faulks:** This is a sort of omnibus question. What changes, if any, would you make to the Act, to the codes of practice on the Mental Capacity Act or, indeed, to the deprivation of liberty safeguards? That may be too big a question and you many want to go away and think about it—subject, of course, to the Chair’s views—and add it to any written submissions you make. However, there may be something on the top of your head that you are burning to get out now.

**The Chairman:** You have been given prior notice, but you may want to reflect further.

**Moira Fraser:** Further reflection would be useful. The Act itself is a good piece of legislation and really moved things forward. The problem lies with interpretation and local implementation. There are some concerns around definitions of deprivation of liberty, the understanding of it and how it is used, and that could perhaps be looked at. There is another issue which could be fleshed out. I was involved in developing the code way back in the mists of time and I still feel it works quite well, but we have concerns around confidentiality and how that is used as a barrier to families—perhaps that needs further looking at in the code.

**Emily Holzhausen:** In addition, I would say that on the whole it is a very sensibly drawn up piece of legislation. How it fits with other legislation, not just the Mental Health Act, is critical; for example, where somebody lacks capacity and shows that they really do not want to have alternative care, but the carer is on their knees and desperate for a break. It is those sorts of situations that are very hard to guide through, where you are balancing the human rights of the family with the rights of the person who lacks capacity. Perhaps we need more thought about where that sits. I do not think the Mental Capacity Act needs to change, but perhaps more thought needs to be given to how the two work together.

**Oi Mei Li:** I agree. I do not think that there need to be any changes to the Act itself, and the code of practice is really good and gives good examples. However, I think there could be some supplementary guidance—the Act has been in place now for a number of years and we have examples of best practice and there are some grey areas with the Mental Capacity Act and the Mental Health Act, as somebody said, around safeguarding and issues like that. Perhaps they could be fleshed out.

We have already touched upon the other things I would like to see; I would like to see information for family carers embedded in the Care Bill and provided from age 14, if possible, during the transition period. Also, making the Court of Protection more accessible, or having another, more local mediation service. The Mental Capacity Act talks about quite clear-cut decisions, where you have a singular decision to be made, and quite often in life decisions are quite complex and there are a number of decisions that can be made. If it was embedded in person-centred planning, care planning, et cetera, it would really help professionals and families to work together towards a common goal or an agreement before it escalates.

**Baroness Barker:** I have a question you have not been asked, so I want to give you notice and ask you to go away and think about it. When we did the work on the Act, we never thought about the impact of technology, communications and so on: it was
not a factor back then. It is something we thought that we might now look at. We have not pursued it at great length, but given that you work with carers, will you go back and ask your networks whether the ways in which all sorts of things are changing, and communications technology is changing, is having an impact on them as carers?

**The Chairman:** I also ask you to reflect on the question that Lord Faulks asked about specific changes to the Act or to the code. Oi Mei mentioned some specific points, but if there are other points where you think the system could be improved by changes to the code, if you could identify the defect and the improvement and put it in writing, it would be extremely helpful to us. With that, I would like to thank you for your attendance today and encourage you, if you have not already done so, to consider submitting written evidence to us. Thank you very much.
Carer’s Trust – Written evidence

About Carers Trust

Carers Trust is the UK’s largest charity for carers. With local Network Partners we work to improve support, services and recognition for carers in communities across the UK. We offer practical help, both in and outside the home, desperately needed breaks, information and advice. Together with Network Partners we work as one organisation united by a shared vision for carers.

Our vision is of a world where the role and contribution of unpaid carers is recognised and they have access to the quality support and services they need to live their own lives.

This response draws on the extensive consultation with carers and Carers Trust Network Partners. Carers Trust leads on the Triangle of Care project and has been working across England with carers and mental health professionals to improve the inclusion of carers in service delivery and ensuring that they receive appropriate and timely information, advice and support.

1. Summary

1.1 The response is divided into sections covering the questions that the committee has presented, we focus on those questions we particularly welcome or believe need further clarification. It provides evidence and recommendations to the House of Lords Committee on the following areas:

- Section 2: General comments and areas for further clarification
- Section 3: Overview of Act achievements and appropriateness of principles
- Section 4: Implementation of the principles into frontline practice
- Section 5: Understanding of the Act by carers
- Section 6: The involvement of carers in decision making
- Section 7: The Court of Protection and The Office of the Public Guardian

2. General Comments and Areas for Further Clarification

2.1 Carers Trust welcomes the establishment of a House of Lords Select Committee to consider and report on the Mental Capacity Act (2005) and the opportunity to respond to the Committee’s call for evidence.

2.2 Carers Trust’s view is that the Mental Capacity Act has fundamentally been a positive development in the legal framework and that the Act itself meets the needs of those who lack capacity and carers who support them. The Act set into law the rights of those with fluctuating capacity or those with no capacity; in addition it set out how families and carers should be involved in decision making processes and their knowledge sought to ensure decisions are made in the best interests of the person lacking capacity.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
2.3 Although we do not feel that the Mental Capacity Act requires amendment, we do feel that there needs to be clarity about implementation and use especially in relation to the involvement of carers.

2.4 Carers have provided evidence to Carers Trust that suggests that frontline staff appear to not have a clear understanding of the principles of the Mental Capacity Act and involving carers in decision making processes. (Livingston Et Al, 2010)

2.5 Many carers (especially those caring for someone with a mental health problem) do not have an awareness of, or a clear understanding of the Mental Capacity Act. Often many are not informed of their requirements until a point of crisis occurs or the need for a Lasting Power of Attorney becomes urgent. A Carer Group in Northamptonshire (comprising 12 carers) was consulted on the Mental Capacity Act. None of the 12 carers present had heard of the MCA, although some of them had awareness of its provisions in relation to financial decisions but were not aware that this was part of the Mental Capacity Act.

2.6 Carers have provided evidence of the complicated, lengthy and expensive process of obtaining a Lasting Power of Attorney (see points 7.1 & 7.2 for specific detail). It has also been highlighted that carers are not being informed of this provision early enough or through the appropriate channels.

2.7 Carers Trust would welcome clarification within the guidance on MCA about the inclusion of carers in best interest decision making and emphasis on appropriate implementation by front line staff.

2.8 Clarity and guidance would be welcomed on the use of Lasting Powers of Attorney and Deputyships. Carers Trust would hope that the process is simplified including the costs as a number of carers (during our evidence request) have cited costs of over £1000 for the Lasting Power of Attorney process. A carer recently contacted Carers Trust asking for clarity on her need to become a Deputy for her adult daughter with learning disabilities as she had been given three different conflicting recommendations from three different solicitors.

3. Overview of Act – Achievement of Aims and Appropriateness of Principles Committee Questions:

Question 1 – To what extent has the Mental Capacity Act (2005) achieved its aims?
Question 3 – At the core of the MCA are its principles and definitions of capacity and best interests. Are these appropriate?

3.1 In general Carers Trust feels that the Mental Capacity Act has achieved its aims. There is a clear framework that exists to enable those lacking capacity and their carers to make decisions and challenge decisions made for and about them. However, the feedback we have received from carers suggests that they are not being consistently informed of the Mental Capacity Act and what it means for them and the person they care for. In addition research findings demonstrate that the principles are well received, however the complexity of the MCA and the implications for carers makes the need for improved promotion to carers and those
supporting them imperative for the process of “best interest” decision making to work.

A group of carers supporting a partner with Early-Onset Dementia who attend a carer group in Rotherham were interviewed about the MCA (after a request for evidence by Carers Trust for this consultation) had an awareness of the Act but had not been given full details about what it meant and had not been supported to discuss with the partner the implications for the future when their capacity would diminish.

4. Implementation of the Principles into Frontline Practice

Committee Questions:

Question 4 – To what extent have the five principles of the MCA been implemented in frontline practice? What evidence is available to assess this? Is there a satisfactory balance between enablement and protection?

4.1 Carers Trust has found that implementation of the five principles by frontline staff is inconsistent. Carers are not receiving information on what the Mental Capacity Act is and the principles that underpin it. A group of 74 mental health carers surveyed in South Yorkshire stated that they had little understanding of the MCA; 17 had heard of the MCA but when quizzed had little understanding of it. However, all felt (when the principles had been explained to them) that staff were not implementing the five principles consistently.

4.2 Where a best interest decision is being made this can tend to be based on one professional’s decision and carers’ knowledge and experience of the individual are not sought or taken into account, see case study below:

Case Study

A man with learning disabilities who uses a touch talker but has sufficient skills to preside as Vice Chair of a local self-advocacy group. A decision needed to be made about his capacity to understand a tenancy. The social worker deemed that he did not have the capacity to agree to a tenancy. However his parents felt that if you explained to him that he needed to get his rent paid on time, needed to keep the house clean and that he must consider others by not making lots of noise- he would have understood those concepts.

4.3 We would like to see clarification in guidance that carers’ knowledge of an individual, including any wishes that have been expressed by them should be taken into account and sought more robustly than at present. Current guidance recommends seeking the knowledge of carers and including and supporting them in decision making as good practice. In addition Carers Trust would welcome a requirement in the guidance that carers are provided with information on the Mental Capacity Act to enable them to understand their responsibilities as well as their rights. Currently there is no specification that this is a requirement for professionals who come into contact with carers.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
5. Understanding of the Act by Carers

Committee Questions

Question 7 - Is the Act widely known and understood by those directly affected by it and by their non-professional carers? To what extent does the Act provide protection and reassurance for informal carers? Has the right balance been struck between protection of the carer and protection of the individual who lacks capacity?

5.1 Carers Trust has found through consultation with Network Partners and carers that generally carers have limited understanding of the Mental Capacity Act. A number of Network Partners consulted with their carer groups (carers of people with dementia and carers of people with an enduring mental health problem) and less than half of those consulted had heard of the Mental Capacity Act, of those that had heard of it their knowledge was very limited.

5.2 Carers of people with a learning disability tended to have a stronger awareness of the Mental Capacity Act; however those who had a stronger knowledge acquired this through self-education, in particular searching the internet, speaking to other carers and being supported by third sector carers organisations. Other carers of people with a learning disability still felt that they did not fully understand how it applied in practice.

5.3 There was a lot of confusion from carers of people with a severe mental health problem about where the boundary between the Mental Health Act and the Mental Capacity Act was; in addition this group of carers were unclear about the idea of capacity when the person they cared for was admitted to hospital under a Section; carers seemed to perceive the use of a Section being linked to a person lacking or losing capacity.

5.4 Although some carers felt that the Act provides protection for those lacking capacity, they did not consistently feel that it afforded them this protection. One carer who cares for a son with autism stated “I think that the Act gets in the way sometimes and that professionals, services, hide behind it and use it as an excuse not to engage with carers. In some instances, it might not be advisable to engage with a carer; however, in some cases, common sense goes out of the window when the patient/service user clearly has limited or fluctuating capacity can only participate with support and help from the carer, but the professional or service refuses to include the carer”.

5.5 Carers Trust would welcome clarification in the guidance and regulations applying to the implementation of the Mental Capacity Act on the following:

- Provision of information on the Act as a requirement to carers and family
- Clarity on the need to include and inform carers about Advance Decisions and Best Interest Decisions to carers

6. The Involvement of Carers in Decision Making

Committee Questions

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Question 12 – Has the MCA fostered appropriate involvement of carers and families in decision making?

6.1 Carers Trust does not feel that the MCA has fostered appropriate involvement of carers and family in decision making. Carers Trust would like to see a stronger requirement to involve family and carers in decision making as part of the MCA.

6.2 Carers Trust has found carers have had particularly poor experience of appropriate involvement by health professionals. Carers of people with a severe mental health problem often find that they are not being consulted or involved in decisions relating to the care of the person they care for. The case study below highlights the medical professionals not fully informing and including the carer to enable her to understand and comment on their decision making process. The additional comment about people with Down’s Syndrome having a short life expectancy presents a question as to whether a best interest decision making process was being adhered to.

6.4 Carers Trust has found through consultation with carers that their valuable knowledge is not being used when making a best interest decision; this is a particularly concern when it may be a professional who does not know the individual well.

6.5 Carers Trust would request stronger emphasis on the requirement for family and carers to be involved in decision making including best interest decisions. In addition Carers Trust would like to see a requirement for professionals to demonstrate their inclusion of carers in decision making processes.

7. The Court of Protection and the Office of the Public Guardian

Committee Questions:

Question 18 – Are the Court of Protection and the Office of the Public Guardian sufficiently understood and accessible to all? Are they operating effectively and successfully?

Question 20 – What concerns, if any, are there regarding the costs associated with registering an LPA, or with making an application to the Court of Protection?

7.1 Carers Trust has found through consultation with carers that carers are experiencing financial difficulties and personal anxiety through the complexity of applying to be an LPA. A number of carers who provided feedback to our request for evidence cited costs of over £1000 for the process if using a solicitor; those who undertook the process themselves stated the costs were far lower but the process was complex and onerous.

7.2 Carers Trust would seek clarity on the needs and use of LPA and Court of Protection powers as carers are be placed into financial hardship for small amounts of money and the time for the processing of an LPA can have a significant impact on a carer’s finances.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Carer's Trust – Written evidence

30 August 2013

References:


Peel E. and Harding R. (2013), 'It's a huge m'aze, the system, it's a terrible maze". Dementia carers’ constructions of navigating health and social care services', Dementia, published online July 13 [http://dem.sagepub.com/content/early/2013/07/02/1471301213480514.abstract]


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Papers provided by Mr Justice Charles

The following papers are provided by Mr Justice Charles, Judge in Charge at the Court of Protection. They consist of an information sheet with six annexes. The annexes are:

Annex 1 A synopsis of the cases that the Committee members may be able to observe on their visit.
Annex 2 The Court of Protection Organisation map.
Annex 3 The report of the ad hoc Rules Committee in July 2010.
Annex 4 Statistics prepared for a meeting in September 2013.
Annex 5 Table of hearings by High Court Judges in London.
Annex 6 Table of hearings by other judges in and all judges out of London.

Mr Justice Charles has also requested that the information pack provided to applicants be provided to the Committee. This is included at the very end of the visit pack.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
INFORMATION SHEET

1. This has been prepared for the visit to the Court of Protection of members of the House of Lords Select Committee on the Mental Capacity Act on 20 November 2013 and for the use of the Committee thereafter.

2. It is accompanied by Annexes, listed in the attached index.

Some Dates and Comments

<table>
<thead>
<tr>
<th>Year</th>
<th>Event</th>
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<tbody>
<tr>
<td>2003</td>
<td>Mental Capacity Bill</td>
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<tr>
<td>2005</td>
<td>Mental Capacity Act</td>
</tr>
<tr>
<td>April 2007</td>
<td>Intended start date</td>
</tr>
<tr>
<td>October 2007</td>
<td>Actual start date</td>
</tr>
<tr>
<td>2008/9</td>
<td>Intended Rules review (which did not happen)</td>
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<tr>
<td>End 2009</td>
<td>Ad hoc Rules Committee formed</td>
</tr>
<tr>
<td>July 2010</td>
<td>Ad hoc Rules Committee reported making 10 recommendations, all of which were accepted by the President and the Department</td>
</tr>
<tr>
<td>December 2011</td>
<td>One of the recommendations of the ad hoc Rules Committee was implemented by the introduction of Rule 7A (see SI 2011/2753). It allowed court officers to be authorised to exercise the jurisdiction of the Court in defined cases. It is supported by a Practice Direction.</td>
</tr>
<tr>
<td>2012</td>
<td>The Court and its administration moved from Archway to the Thomas More Building</td>
</tr>
<tr>
<td>2013</td>
<td>The Court and its administration is moving again, this time to First Avenue House, High Holborn. This is expected to be a permanent home for the Court.</td>
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</table>

The jurisdiction of the Court

3. This is conferred by statute and the Court does not have an inherent jurisdiction or an administrative law jurisdiction. So it has no jurisdiction over a vulnerable adult who has the relevant capacity and, subject to some arguments under the Human Rights Act, no power to overturn or declare unlawful decisions of public authorities concerning the provision of care or support on administrative law (judicial review) grounds.

4. The Court has inherited, with changes, the property and affairs work of the old Court of Protection. In terms of numbers this work comprises the great majority of the work of the Court (around 95%). Also, around 93% of those applications are non-contentious.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
5. This split of work introduces a need to recognise that a significant majority of the applications to the Court involve persons who have lost capacity to manage all or aspects of their financial affairs and whose families and carers need court orders to enable those affairs to be managed. Most of those applicants are honest, loving and supportive family members or carers who want a speedy result and understandably would resent an intrusive process to check their bona fides.

6. Sadly, this does not apply to all applicants and so the Rules contain some provisions directed to demonstrating bona fides and the Office of the Public Guardian has a regulatory role in respect of Deputies appointed by the Court.

7. The Court has inherited with changes the health and welfare jurisdiction of the High Court which was based on its inherent jurisdiction. That inherent jurisdiction survives for vulnerable adults.

8. There are significant differences between the issues that arise in the two types of work.

9. The policy directive at the time the Rules were drafted was that one process should fit all. As identified by the ad hoc Committee this caused, and is still causing, problems.

**The judges and location of the Court**

10. Before recent changes, to be a judge of the Court a person had to be the President of the Family Division, the Chancellor, a High Court Judge, a Circuit Judge or a District Judge and be nominated to sit in the Court. The statute also provides that there is to be a President, a Vice President and a Senior Judge. They have been and are respectively the President of the Family Division, the Chancellor and Judge Lush (who was the Master of the old Court of Protection). Since June 2011 there has also been a Judge in Charge whose role is broadly to support, advise and make recommendations to the President and Vice President.

11. Four District Judges and the Senior Judge are based in London as are the authorised officers of the Court and its administration. This is, therefore, the judicial and administrative workforce that deals with the vast bulk in terms of numbers of the applications made to the Court (i.e. non – contentious and contentious property and affairs applications). They also deal with all other aspects of the work, all of which has to be issued in London. So they will deal with directions, decide many cases on paper, decide some cases after a hearing and transfer some cases to other judges and places for a hearing.

12. All High Court Judges are nominated to sit in the Court although the only ones who do so regularly are judges of the Family Division. A total of about 90 Circuit and District Judges who are mainly based outside London are nominated to sit. Many sit more than others and some do not sit at all. In the main this arises because initially there was over nomination to try to ensure that there were nominated judges throughout the country.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
13. In his first report to the President and Vice President in November 2011 the Judge in Charge recommended that as a matter of urgency a process for the transfer of cases to High Court Judges and to judges on the circuits be agreed and implemented. He reported that this recommendation related to the issues about which he had heard the most complaints from the judiciary. Since then attempts have been made to achieve this but they have not succeeded. It is understood that the present reason for this relates to funding and resource arrangements within HMCTS.

14. There can be no doubt that the present ad hoc arrangements for transfer are unsatisfactory and are causing problems and justifiable annoyance to litigants, practitioners, judges and court staff.

The two main problems relating to the day to day performance of the Court of Protection

15. These are the long running problems relating to the failure to make amendments to the Rules and to introduce a process for transfer of cases to the circuits. The solution to these problems is not in the hands of the Court. It is to be hoped that the steps being taken by the President will lead to these long running problems being addressed and solved.

16. Apart from changes to deal with the making and pursuit of claims and appeals Rule change is now needed to address transparency and disclosure of papers for particular purposes (the existing Rules having been drafted in general terms against a background of debate over equivalent issues in the Family courts).

Workload and improvements in performance

17. Part of the background to the setting up of the ad hoc Committee at the end of 2009 was that in large measure due to an underestimate of the workload of the new Court a large backlog of work and consequent delays had built up.

18. The Rule change made in December 2011 that enabled authorised officers to do non-contentious property and affairs work was a major factor in bringing about a dramatic reduction in the backlog of work awaiting allocation to a judge and so delay.

19. There has also been an increase in the complement of the District Judges sitting in London and an improvement in maintaining that complement week by week through the use of visiting judges. These visits have also created and promoted relationships with judges on the circuits and have provided those judges with experience in circumstances where they can readily consult experienced colleagues.

20. Having given up on Rule change against which new forms could be prepared the District Judges have drawn up a new set of forms which have been road tested and which it is hoped will be much more user friendly. It is hoped that they will be introduced in early 2014.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
21. Since 2007, the Court has also introduced against the background of the existing Rules a number of procedural and other changes including: changes to the notification of service forms, the provision of a process for providing interim orders to meet an urgent need and reducing duplication, a removal of the original direction that Deprivation of Liberty cases had to be heard by a High Court Judge.

22. The Court has also sought to promote an informal system for transferring cases to the circuits. At High Court level this is being achieved by cases being put before the Liaison Judge for the relevant circuit and that judge directing how it is to be dealt with on the circuit. At District and Circuit Judge level it is being dealt with largely through the relationships that have been built up between judges and staff in London and on the circuits through them working together and the discussions about and drafts of a protocol for such transfers as and when appropriate funding and resources have been agreed and implemented.

23. From 2010 the Court has adopted the “Lean” continuous model. Improvements have enabled the administrative and judicial resources to shorten turn round times. The time it takes to deal with an application also includes periods when the Court cannot do anything because it is waiting for someone else to do something (e.g. file evidence) but the improvements made have enabled the Court to maintain or improve its performance assessed by turn round times for individual tasks and its Key Performance Indicators (KPI) against a background of an ever increasing workload (around 25% since 2009) and a staff reduction of 20% since 2009.

24. The following tables show this:

<table>
<thead>
<tr>
<th>Total applications received per year</th>
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<tbody>
<tr>
<td><strong>2009</strong></td>
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<tr>
<td><strong>2010</strong></td>
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<td><strong>2011</strong></td>
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<tr>
<td><strong>2012</strong></td>
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<td><strong>2013</strong></td>
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<table>
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<tr>
<th>Total Orders made per year</th>
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<tr>
<td><strong>2009</strong></td>
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<td><strong>2010</strong></td>
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<td><strong>2013</strong></td>
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In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
CoP performance against KPIs 2009-2013

<table>
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<tr>
<th>KPI</th>
<th>Description</th>
<th>2009/10</th>
<th>2010/11</th>
<th>2011/12</th>
<th>2012/13</th>
</tr>
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<tbody>
<tr>
<td>1</td>
<td>In 95% of cases we will contact the applicant within 20 working days of receipt of the formal application</td>
<td>93%</td>
<td>98%</td>
<td>99%</td>
<td>99.57%</td>
</tr>
<tr>
<td>2 (i)</td>
<td>In 75% of applications where no oral hearing is directed the court will give a direction within 16 weeks</td>
<td>78%</td>
<td>74%</td>
<td>76%</td>
<td>72%</td>
</tr>
<tr>
<td>2 (ii)</td>
<td>In 98% of applications where no oral hearing is directed the court will give a direction within 20 weeks</td>
<td>85%</td>
<td>81%</td>
<td>81%</td>
<td>79%</td>
</tr>
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Mr Justice Charles

Judge in Charge of the Court of Protection

November 2013.
Annex 1 – A synopsis of cases that the Committee Members may be able to observe

MRS JUSTICE E.KING
MON 18 – WED 20 NOVEMBER 2013 DAY 3 of 3

This case is a personal welfare, residence and parental contact application where “P” has been residing in a care home in Surrey for 11-12 years. He is the third son of the family to be placed in residential care. His brothers are resident in East Sussex care home/s. The PCT wishes the court to determine that P no longer meets the criteria for NHS continued healthcare funding and that this is the responsibility of the Local Authority. P resides in a care home for people with severe learning disabilities. His parents disagree with the placement and have expressed grievances about the care being provided. Placement of P is at risk as a dispute over the funding of Ps care is in issue.

The parents have made several appeals and attempts to discharge the care orders made in this and the previous case(s) involving his brothers. Previous proceedings in respect of two older brothers of P have been litigated and the parents seek to reopen these cases.

They make claims under Article 8 of The Human Rights Act. The original application was made as a result of fears as to what the family may do once P reached 18 years old and the existing court orders expire.

MR JUSTICE HAYDEN
WED 20 – FRI 22 NOVEMBER 2013 DAY 1 of 3

In this case “P” is a 35 year old male with severe learning disabilities, autism and challenging behaviours. P moved to a residential care home in May 2011. The proceedings are for a declaration that it is in Ps best interest to reside in residential care in a new placement. Mother wishes P to return home to live with her and seeks unrestricted and unsupervised contact with P and overnight stays at home as well as additional contact on special occasions. The Applicants do not consider increased contact would work well and this issue is to be determined at court.

MR JUSTICE BAKER
WED 20 November 2013
Directions on transfer to the High Court – 2.5 hours

In this case P is a 46 year old female with moderate to severe learning difficulties, with no capacity to litigate or decide where she should reside. She has been in residential care for 24 years and the care home is to be closed by the Council.

The Application is for a declaration that it is in P’s best interests to move to such other suitable accommodation as would meet her needs and that it is lawful for the Applicant to move P. Her mother (as litigation friend) on behalf of P opposes this and seeks a re-assessment of P’s needs. There may be parallel proceedings for Judicial Review and Injunction in the Administrative Court that these proceedings be

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heard by a High Court Judge at the same time as the proceedings in the Court of Protection. Her Deputy seeks a reassessment of Ps needs and a care plan, and claims a violation of Ps rights under Article 8 of the Human Rights Act.
In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Mr Justice Charles (Court of Protection) – Written evidence

Annex 3

Please see link attached.


In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Annex 4 - Statistics prepared for a meeting in September 2013

Agenda Item: 3

Date of Meeting: September 2013

Title: Court Statistics

Purpose: For information

Author: Jen Matthews

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
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In August 99.65% applications issued within the 20 days KPI and 65.01% were issued within 5 days.

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In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Mr Justice Charles (Court of Protection) – Written evidence

Quarterly Figures

<table>
<thead>
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<th></th>
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<th>Jul-Sep</th>
<th>Oct-Dec</th>
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<td>P&amp;A orders issued</td>
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<td>5290</td>
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<td>P&amp;A deps appointed</td>
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<td>H&amp;W orders issued</td>
<td>31</td>
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<td>202</td>
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<td>Archway/Thomas</td>
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<td>87</td>
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<td>LPA Objections</td>
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<td>22</td>
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<td>EPA Directions</td>
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<td>47</td>
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<td>LPA Validity apps</td>
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<td>76</td>
<td>127</td>
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Breakdown of P&A Applications

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
## Breakdown of P&A Orders

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Annex 5 – Table of Hearings by High Court Judges in London

<table>
<thead>
<tr>
<th>DATE</th>
<th>&lt; 2.5 hrs</th>
<th>2.5 hrs</th>
<th>1 day</th>
<th>2 days</th>
<th>3 days</th>
<th>4 days</th>
<th>5 days</th>
<th>over 5 days</th>
<th>( ) total days</th>
<th>total number of hearings</th>
<th>CASE count</th>
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</thead>
<tbody>
<tr>
<td>2010</td>
<td>106</td>
<td>16</td>
<td>21</td>
<td>13</td>
<td>12</td>
<td>4</td>
<td>1</td>
<td>2</td>
<td>(26)</td>
<td>175</td>
<td>84</td>
</tr>
<tr>
<td>2011</td>
<td>177</td>
<td>24</td>
<td>30</td>
<td>16</td>
<td>13</td>
<td>2</td>
<td>4</td>
<td>2</td>
<td>(20)</td>
<td>268</td>
<td>128</td>
</tr>
<tr>
<td>2012</td>
<td>158</td>
<td>29</td>
<td>29</td>
<td>15</td>
<td>11</td>
<td>1</td>
<td>3</td>
<td>2</td>
<td>(13)</td>
<td>248</td>
<td>126</td>
</tr>
<tr>
<td>2013</td>
<td>92</td>
<td>22</td>
<td>23</td>
<td>3</td>
<td>7</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>(10)</td>
<td>151</td>
<td>78</td>
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</table>

These figures reflect a calendar year January - December. It has not been possible to provide a breakdown of the types of cases. Statistics of specific Court Of Protection hearings did not commence until April 2010. The cases of 5 days or over were invariably medical cases. Each case transferred from the Court Of Protection is considered by a High Court Judge and was listed for immediate directions, followed by a full hearing. In some cases additional applications were made in this court by the parties before the conclusion of the matter. An increase in hearings during 2011 and 2012 may be a reflection of the high number of Deprivation of Liberty safeguard cases in the Family Division. In 2013 (to end October) there can be seen a reduction in hearings on previous years, and this can be attributed to an informal regionalisation of cases, where matters are referred to the Family Division Liaison Judge and often transferred to be heard on the circuit, either by a High Court Judge or a Circuit Judge.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Mr Justice Charles (Court of Protection) – Written evidence

Annex 6 – Table of hearings by other judges in and all judges out of London

Hearings from Jan 2009

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<thead>
<tr>
<th>Jan</th>
<th>Feb</th>
<th>Mar</th>
<th>Apr</th>
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<th>Jun</th>
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<td>37</td>
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<td>45</td>
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<td>45</td>
<td>48</td>
<td>42</td>
<td>28</td>
<td>30</td>
</tr>
<tr>
<td>Regional 2010</td>
<td>64</td>
<td>70</td>
<td>88</td>
<td>58</td>
<td>66</td>
<td>83</td>
<td>60</td>
<td>40</td>
<td>53</td>
<td>55</td>
<td>63</td>
</tr>
<tr>
<td>Archway 2011</td>
<td>28</td>
<td>14</td>
<td>41</td>
<td>30</td>
<td>34</td>
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<td>47</td>
<td>20</td>
<td>56</td>
<td>41</td>
<td>71</td>
</tr>
<tr>
<td>Regional 2011</td>
<td>49</td>
<td>45</td>
<td>56</td>
<td>52</td>
<td>38</td>
<td>53</td>
<td>39</td>
<td>49</td>
<td>51</td>
<td>60</td>
<td>58</td>
</tr>
<tr>
<td>RCJ 2012</td>
<td>55</td>
<td>60</td>
<td>52</td>
<td>35</td>
<td>117</td>
<td>67</td>
<td>95</td>
<td>33</td>
<td>86</td>
<td>120</td>
<td>107</td>
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<tr>
<td>Regional 2012</td>
<td>33</td>
<td>59</td>
<td>60</td>
<td>59</td>
<td>53</td>
<td>56</td>
<td>55</td>
<td>55</td>
<td>41</td>
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<td>RCJ 2013</td>
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<td>56</td>
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<td>144</td>
<td>109</td>
<td>44</td>
<td></td>
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<tr>
<td>Regional 2013</td>
<td>59</td>
<td>59</td>
<td>37</td>
<td>77</td>
<td>70</td>
<td>72</td>
<td>47</td>
<td>70</td>
<td></td>
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</tbody>
</table>

(N.B. This chart is also provided in annex 4 but has been requested by Mr Justice Charles to also be reproduced here)

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Annex 7 - Papers provided by Jen Mathews, Court Manager at the Court of Protection

Contents:

1. Breakdowns of: hearings as opposed to paper applications in the Court of Protection; Property and Affairs Applications; Health & Welfare Applications; Waiting Times in the Court of Protection; and Judicial Box Work history and its current state.

2. Breakdown of the type of Property and Affairs Applications and Orders.

3. Information on the Judiciary in the Court of Protection and the training of new Regional Judges.
Mr Justice Charles (Court of Protection) – Written evidence

Paper 1 – Breakdowns of: hearings as opposed to paper applications in the Court of Protection; Property and Affairs Applications; Health & Welfare Applications; Waiting Times in the Court of Protection; and Judicial Box Work history and its current state.

Hearings as opposed to paper applications in the Court of Protection
In 2009/10 of the 19528 applications received, 1343 hearings took place (6.87%)
In 2010/11 of the 21042 applications received, 1121 hearings took place (5.33%)
In 2011/12 of the 23093 applications received, 1176 hearings took place (5.09%)
In 2012/13 of the 24586 applications received, 1570 hearings took place (6.38%)

Property and Affairs Applications and Health & Welfare Applications
In 2009/10 of the 19528 applications received, 1561 were Health & Welfare applications (7.99%)
In 2010/11 of the 21042 applications received, 1169 were Health & Welfare applications (5.55%)
In 2011/12 of the 23093 applications received, 1119 were Health & Welfare applications (4.84%)
In 2012/13 of the 24586 applications received, 1271 were Health & Welfare applications (5.17%)

Waiting Times in the Court of Protection – how long would an uncontested application take?
From a recent study completed in June 2013, the following details were concluded:
The median waiting times for applications received (given that there is a maximum 42 days statutory service period included) as follows:
In 2009 – 13 weeks
In 2010 – 11.3 weeks (7.75% increase in applications received)
In 2011 – 10.7 weeks (9.75% increase in applications received)
In 2012 – 11.3 weeks (6.47% increase in applications received)
In 2013 (to June) – 11.1 weeks (12.1% increase in applications received so to August 2013)

Judicial Box Work
Figures collected from December 2010:
Pre December 2010, 1159 applications, oldest at 24 days
March 2011, 2456 applications, oldest at 46 days
September 2011 (Lean), 613 applications, oldest at 16 days

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November 2013 averaging, 250 applications at any one time, oldest 10 days

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Breakdown of P & A Applications
This is a detailed analysis of the differing types of property & affairs applications made to the court. They are all applications for orders relating solely to property and financial matters – either through the appointment or discharge of a deputy or through a “single” stand alone order. (with the exception of the hybrid deputy application)

Property & Affairs Deputy - an application for the appointment by the court of a deputy to manage the incapacitated persons (“P”) property and financial affairs.

Hybrid Deputy – an application for the appointment by the court of a deputy to manage both property & financial affairs, and personal welfare matters.

Interim Directions – an application made with the first application (for the appointment of a deputy) for urgent directions required by “P” – for example urgent release of funds to meet residential care home fees prior to the appointment of a deputy.

App within Proceedings – an application after the first application has been issued by the court requesting directions/orders additional to those requested in the first application and prior to the appointment of the deputy.

Property & Affairs - an application for a single (stand alone) order where the appointment of a deputy is not required.

Hybrid (P&A and H&W) an application for a single (stand alone) order dealing with both property & affairs and personal welfare where the appointment of a deputy is not required.

New Trustee - an application for an order to appoint a new trustee(s) where property or land is jointly held and “P” is a trustee.

Will, Gift &Settlement – these are applications for orders to dispose of or vary “P”s estate in the future. Either through the execution of a fresh will, or Court consent to a statutory will, approval of lifetime gifts or creation or variation of the terms of a settlement.

Declaration – an application (see Wills etc above) for a declaration that “P” has testamentary capacity and can give instructions for the making of a will or codicil.

Streamlined Procedure – an application made by a deputy subsequent to their appointment for additional powers or variation of existing powers/restrictions.

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Mr Justice Charles (Court of Protection) – Written evidence

**Discharge Deputy (Recovery)** – an application where “P” is believed to have recovered capacity to manage their property and financial affairs and a deputy is therefore no longer required to act for “P”.

**Discharge Deputy (Other)** - an application to discharge the appointed deputy.

**New deputy Order** - an application for a deputy to be appointed to replace a deputy who has either died, or wishes to be released from their duties.

**Property & Affairs Deputy (interim)** – an application to appoint a deputy immediately on a time restricted basis pending the appointment of a substantive deputy.

**Breakdown of P & A Orders**

This is a detailed analysis of the differing types of property & affairs order made by the court. They are all orders relating solely to property and financial matters.

**Property & Affairs Deputy** - An order appointing a deputy to manage “P”’s property and financial affairs.

**Streamlined Conversion** - An order made appointing a deputy who was formerly appointed as receiver prior to the MCA 2005, implemented October 2007.

**Interim Directions** - An order provided to deal with an urgent property or financial matter, pending the appointment of a deputy.

**Time Limited – replacement order** - A subsequent order to re-appoint an existing deputy, or otherwise provide directions, when a time bound appointment has expired.

**Property & Affairs** - An order made over a single asset or providing authority to do one thing and not appointing a deputy. For example to enter into a tenancy agreement.

**Discharge Deputy (Recovery)** - An order discharging the deputy and restoring “P” to management of his own financial and property affairs when he has re-gained capacity.

**Discharge Deputy (Other)** - An order discharging the deputy

**New Trustee** - An order appointing a new trustee(s) to act in place of “P” as trustee.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Mr Justice Charles (Court of Protection) – Written evidence

**Will, Gift & settlement** - An order confirming “P” may execute a Will, a statutory will may be made for “P”, large gifts may be made from P’s estate, or a settlement on which “P” has an interest be varied or created.

**Property & Affairs Deputy (Interim)** - An order appointing a deputy on an interim basis, time bound usually for 3 or 6 months.

**Replacement Order** - An order “up-dating” a deputy’s powers who was appointed using a transitional order on the introduction of the MCA 2005, implemented October 2007.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Mr Justice Charles (Court of Protection) – Written evidence

Paper 3 – Judiciary in the Court of Protection and Training of new Regional Judges

Judiciary in the Court of Protection

There are 6 allotted Judiciary to the Court of Protection.

There are 3 full time and 3 part-time Judiciary, equal to 5 full time Judges.

There have been considerable increases to the Regional Judiciary in order to improve coverage across the country with 86 regional Judges and 5 High Court Judges now in the Judicial Team.

Training of new Regional Judges

The Judicial College provides specialist training on CoP as and when it is needed. Training for 23 judges is scheduled for later this month.

The court also provides judicial training for the newly appointed. The judges and staff have set up a training plan so that the newly appointed sits with an experienced judge for at least 2 days and then the Authorised Court Officers give help and advice for 1 day in relation to box work and agreed practices and explain the full set of template orders in order to improve efficiency and quality. All new judges who wish to have practical training will have completed the Court of Protection practical training by the end of 2013.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
We appreciate this opportunity to submit evidence to this select committee. Our focus is on patients of Limited English Proficiency (LEP) (including many people of Black and Minority Ethnic (BME) origins, and more recent migrants of European origin). However, language impairment also affects people with hearing loss (Deaf), some sight-loss conditions, and those with Learning Disabilities.

The diagnosis and treatment of mental health disorders requires accurate and adequate communication, which accommodates any subtleties and nuances that may be involved. Language disturbance is a key diagnostic indicator for mental health states. If adequate communication is not possible, where there is insufficient shared language, inherent risks arise to both patients and health care providers. In such situations, language support is needed for all parties.

The Human Rights in Healthcare project, an initiative to embed the HRA in all that the NHS does both in actions and in language was launched in Liverpool in 2012. Jan Cambridge was present and met the FREDA Fighters, a group of nine adults with intellectual disabilities who had studied their human rights. The group developed the idea that Fairness, Respect, Equality, Dignity and Autonomy could become a person whose opinion they could refer to. One of their group had said “Freda sounds like a nice lady.” This group were all native English speakers.

Freda means to me that you’re learning to stand up for yourself but also learning about your human rights ... you start to learn to grow within yourself.” (Service User FREDA Fighters 2012) (in Roberts et al 2013:17).

In this submission, we are hampered in quantifying the need by the absence of well defined service monitoring data which identifies the numbers of LEP patients receiving care, of what type, where and in which languages, as well as the numbers who could benefit from such care if they had access to it. It is generally recognised, however, that the process of migration itself can give rise to mental ill health. This is often combined with the absence of reliable health care in previous places of residence and the reluctance, in some cultures, to recognise that need. Timely and effective care promotes the possibility of patients, and their families, living functional lives and therefore not being a burden on the state. Note that LEP patient numbers are not necessarily coterminous with those described as Black and Ethnic Minority patients. Many ‘majority’ white people belong to Non-English language backgrounds. Sign Language (for example), as used by the Deaf community, is increasingly being recognised as a language in its own right.

All public services face challenges since increasing global movement of people is taking place during an economic crisis, and the supply of the necessary language and medical skill-sets has
for some time lagged behind the demand for them. There are three possible options for dealing with the situation:

- to ignore it, which would be imprudent and unprofessional
- to establish short-term compromises, which are likely to be unsafe and lead to unsatisfactory long-term solutions
- to establish carefully planned incremental systems leading to cost-effective satisfactory long-term goals, while optimising available skills with responsibility and accountability. This is the option suggested and will be set out briefly at the end of this submission.

6 In answering this call for evidence we shall, meanwhile, address only those points that relate to the act of communication during interpreted communicative events (ICE). We refer specifically to the call for evidence at point 27 of the overview and to points 10, 13, 15, 16, 18, 22 and 23.

7 Among the many rights that persons with disabilities have is the right to be heard.

All participants, as Sacks (1984) and Goffman (1983) observed, have primary rights to know and to describe their own thoughts and experiences. (Heritage and Raymond, 2005:36).

8 People of Limited English Proficiency (LEP) are at a double disadvantage when communicating with the authorities at a mental capacity assessment. Those who use a spoken or signed language other than English or BSL should have a competent interpreter available as part of their right to autonomy.

The Act does not limit the action that service providers can take to meet different needs, provided the action satisfies the statutory conditions and is a proportionate means [...] of meeting genuinely different needs. [Including] providing services specifically aimed to meet particular needs,” (Equality Act 2010 Statutory Code of Practice, Services, public functions and associations 5.31).

9 It should be noted that the interpreting and translation professions are not yet regulated by statute. The current situation in the language interpreting context (both spoken and signed) is such that professional linguists’ membership bodies like the Chartered Institute of Linguists and the Institute of Translation and Interpreting can only check the professional credentials and qualifications of their members, their own Chartered Linguist members and Chartered Linguists belonging to a qualifying body such as ITI or AIIC. Their professional codes of conduct do not apply to unaffiliated persons.

10 Recent research by Dr Cambridge, “Interpreter output in talking therapy. Towards a methodology for good practice” (2012), indicates that the majority of interpreters working in the NHS may not reach the standards of training and certification needed for interpreting work in medical settings. See Cambridge, J; Singh, S.P; Johnson M.R.D.J (2012). They appear to be the majority of language workers, claiming ‘bilingualism’ as their only professional skill. They are described as ‘professionals’ by agencies contracted to supply services to the NHS only because they are paid.

11 Family and community members have long been recognised as unsuitable to undertake interpreting tasks because of the risk posed to confidentiality and to the fidelity of interpreted messages (Cambridge 2008).

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12 The term ‘Bilingual’ embraces a huge range of competence from being able to count in two languages to the level of an educated a near-native speaker in two languages. In fact the term is not fully defined. It has a sliding scale from pidgin to professional competence, though not necessarily in all aspects of both languages in use. Best practice suggests that interpreted MCA assessments should be the work of the most highly trained and experienced accredited interpreters, who make themselves accountable by their affiliations to Institutes and their codes of professional conduct.

An alternative is the use of healthcare staff possessing a dual combination of language and professional skills where both been developed to the right levels through rigorous selection, training, assessment and supervision. Logistically, this is likely to be a more rarely used solution, given the reported 300 languages spoken in London alone

13 Interpreters, whether qualified or not, affiliated or not, are gatekeepers to the content of messages. That makes them more powerful than any other party to the interview, because nobody else can do their own job until they know both what was said and what was meant. If the individual interpreter lacks relevant degree level qualifications and professional affiliations there is no possibility of calling them to account in the event of an error of theirs causing harm.

14 Interpreting is a profession and a craft. It requires training to at least degree level delivering technical skills, a broad and deep knowledge of both languages offered, both vernacular and technical, as well as sound personal judgement.

15 Decision making should be supported by a professional interpreter with specific training and experience, who is at least a member of CIOL www.iol.org.uk or ITI www.it.org.uk or listed with the national regulator (NRPSI) www.nrpsi.co.uk.

16 It is not the job of government to create professions. It is however part of governing to create the conditions in which developments such as competent, coherent and safe national interpreting, translating and language support services (ITALS) can happen. This was, for example, recognised in a parallel field by the creation of the Health Professions Council as part of the response to the need to regulate health care assistants and other professions active in medical care.

17 Incremental Steps Forward (in summary)

These suggestions are based upon the work carried out by the Institute of Linguists and collaborators, in the UK and the EU, since 1983.

- Quantify general demand, in terms of numbers, languages and locations
- Set out employment arrangements and working conditions to attract people to train
- Train trainers where needed
- Establish nationally recognised training in the required skill-sets, including:
  • Medical interpreters and translators – to be combined with,
  • Health care staff equipped to work across languages and cultures
  • Administrators capable of employing and deploying skills sets
  • Senior health care staff equipped to support, supervise and monitor
  • Functional bilingual staff with dual language and professional skills
- Establish nationally recognised assessments for the above

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Chartered Institute of Linguists Working Group on Language Support in Health and Social Care – Written evidence

Note that such assessments already exist for interpreters and translators (www.iol.org.uk/qualifications)

30th of August 2013

References


From USA

Lau, May; Lin, Hua; Flores, Glenn; (2012). Primary language spoken at home and disparities in the health and healthcare of US adolescents. Diversity & Equality in Health & Care 9,4: 267-280

URL:http://www.ingentaconnect.com/content/rmp/dehc/2012/00000009/00000004/art00006


From EU


URL:http://www.ingentaconnect.com/content/rmp/dehc/2012/00000009/00000003/art00004

From Scotland

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Chartered Institute of Linguists Working Group on Language Support in Health and Social Care –
Written evidence

Irshad, Tasneem; Worth, Allison; Sheikh, Aziz (2007). Are translation and interpretation services a necessity or a luxury? (Guest Editorial). Diversity in Health & Social Care Vol 4,2:87-89


In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Compassion in Dying – Written evidence

About Compassion in Dying

Compassion in Dying is a national charity that supports people at the end of life to have what they consider to be a good death by providing information and support around their rights and choices. We are the leading provider of free Advance Decisions in the UK, run an End-of-Life Rights Information Line which receives in excess of 200 contacts each month, and also conduct and review research into rights and choices in end-of-life care. We also run an end-of-life rights advocacy service (ELRA) which is being piloted in east London with Age UK.

We have only answered those questions relevant to our experience and those planning for their end-of-life care. Our responses focus on Advance Decisions and Lasting Power of Attorney for Health and Welfare (LPA).

Response to call for evidence

Overview and context

1. To what extent has the Mental Capacity Act 2005 (MCA) achieved its aims?

As stated, our focus is on decisions on medical treatments in advance through the use of Advance Decisions and appointment of Lasting Powers of Attorney (LPA), and ensuring such decisions are recorded properly and can be accessed by care professionals.

There did not appear to be any goal-setting around these elements of the law at the launch of the MCA, so whilst the MCA has not ‘failed’ to achieve its aims, much work is needed to improve professional and public awareness of end-of-life rights, and to ensure that care professionals can access patient’s wishes and then act on them. Low public awareness is illustrated by survey evidence which shows 53% of people wrongly believe they have the legal right to make end-of-life treatment decisions on behalf of their next of kin, and 23% of people are not sure whether they have such a legal right or not. Further, only 3% of the public have made an Advance Decision, compared to 82% who have clear views about their end-of-life care preferences.14

Implementation

2. To what extent have the five principles of the MCA been implemented in frontline practice? What evidence is available to assess this? Is there a satisfactory balance between enablement and protection?

The two MCA principles most relevant to end of life care and decision making are: Every adult has the right to make his or her own decisions and must be assumed to have capacity to make them unless it is proved otherwise; and Anything done or any decision made on behalf of a person who lacks capacity must be done in their best interests. In terms of end of life care, information around MCA rights should be promoted so that we can all plan for a time when we may lose capacity.

14 YouGov (2011)

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Compassion in Dying – Written evidence

There is little in the way of evidence to assess how well these principles and our end-of-life rights associated with the MCA have been promoted, and implemented in frontline practice. Research indicates that some doctors would only respect a patient’s Advance Decision preferences if they were in line with their own clinical judgements, suggesting that the MCA is sometimes being breached. However, there are also programmes of care specifically aimed at patients in the last twelve months of life which incorporate Advance Decisions. Preliminary audit shows that these patients’ end-of-life wishes are being respected. So, while there is some data available about patients who are registered in an end-of-life care programme having their wishes respected (and therefore MCA principles being implemented), there is little or no evidence about whether patients who are not registered on such programmes or are not expected to die in the next twelve months have their Advance Decisions respected.

However, whilst evidence from practice is limited, the recent change to the NHS Constitution to cover enabling patients to be involved in discussions and decisions about their end of life care is a positive step and demonstrates that the principles of the MCA are being reflected in official documents of patients’ rights. If this right is realised, in practice we would expect these conversations about end of life planning to both enable patients to make decisions if they wish to, and protect them, as decisions will be made by patients in discussion with doctors and family members, rather than (as at present) potentially being made by doctors in isolation.

3. How effective was the Government’s implementation plan? What measures were taken to ensure that professionals and families of those who lack capacity know about and act in accordance with the provisions of the MCA? Has it led to sustainable change?

In relation to Advance Decisions and LPAs there did not appear to be a dedicated implementation plan, rather a set of publications aimed at educating health and social care professionals about the MCA were disseminated. The Department of Health funded the production of our Advance Decision Toolkit for healthcare professionals which we distribute widely and whenever we can. Feedback on this tool is largely positive; however its reach is limited by the capacity of Compassion in Dying.


17 http://www.devontep.co.uk


19 Preliminary data from Coordinate My Care (London’s Electronic Palliative Coordinating Care System)

20 NHS Constitution 2013: You have the right to be involved in discussions and decisions about your health and care, including your end of life care, and to be given information to enable you to do this.

Where appropriate this right includes your family and carers.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Compassion in Dying – Written evidence

In terms of professionals, initiatives published after the MCA, most notably the Department of Health’s End of Life Care Strategy, have not directly addressed the tools for end of life decision making created by the MCA (Advance Decisions and LPAs), but have promoted a move towards involving patients in decision making at the end of life, and where a patient has lost capacity, asking those close to the patient about whether they had previously expressed opinions on what treatment they would want. In this sense the principles of the MCA are being promoted, albeit not explicitly, in work by the Department of Health.

Currently there are no formal systems for recording Advance Decisions and LPAs for people who are not registered in an Advance Care Plan (however there may be some local initiatives). Such a system would raise the profile of end-of-life rights as well as allowing patient’s wishes to be known about and acted upon.

For members of the public information on MCA rights seems to come from organisations dedicated to promoting these rights, such as Compassion in Dying, or (in some cases) healthcare professionals. The Dying Matters Coalition (set up as a result of the End of Life Care Strategy) aims to encourage a national conversation about death and dying, but tends not to focus on legal rights.

4. Is the Act widely known and understood by professionals required to implement it? How does this differ across different sectors, such as health, social care, banking and others?

There is some evidence that doctors are not knowledgeable about, or engaging with, Advance Decisions21 and that they hold positive views on them; however they are more likely to follow them if they are in line with their clinical judgement which may be in breach of the MCA.22 The British Medical Association’s MCA toolkit,23 and General Medical Council’s guidance24 on end of life decision making sets out how patients must be treated as they approach the end of life, and reflects the MCA principles around involving patients in decision making as far as possible. The RCN and RCGP produced a joint charter on end-of-life care which stressed the need to record decisions.25 It is of note, however, that although this professional guidance is clear about what to do if someone has an AD, it does not set out duties to ask people if they want to make one, or to help them to do so.

As far as we are aware the impact of these documents on cultural and professional practice has not been examined. Monitoring of calls to our Information Line indicate that 10% of Information Line users’ GPs had not heard of Advance Decisions and a small, but significant

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23 http://bma.org.uk/practical-support-at-work/ethics/mental-capacity-tool-kit

24 GMC (201) Treatment and care towards the end of life: good practice in decision making General Medical Council


In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
number (4%) refused to sign it either without being paid to do so, or because of concerns about its validity. An independent academic analysis of over 200 calls to the Information Line revealed, healthcare and legal professionals’ engagement with and understanding of Advance Decisions can be limited.\textsuperscript{26}

I said ‘Well he’s [her husband] made an Advance Decision’. This is the Registrar. He looked at me and said ‘What’s that?’ So I then explained to him. ‘Bring it to hospital’ he said. But I was horrified to think that there was a Registrar who didn’t have a clue.

He [her GP] said ‘When you get the Advance Decision, run it past your solicitor’. So there’s no understanding, they’ve obviously very limited experience of this and don’t understand.

Unfortunately, when I saw my GP, which I had to do, to make an Advance Decision, he sort of didn’t seem to take much notice of it. Anyway, he wasn’t a lot of help, his reaction … It seemed to me as though he was, he didn’t want to be bothered, to be honest.

The solicitor told me that I didn’t need that [Advance Decision] with having a Power of Attorney [for Finance].

Our End of Life Rights Advocacy project in East London suggests there is a demand for training on the elements of the MCA related to end of life which is currently not being met. In the first six months of the project we trained over 215 stakeholders (primarily Community Mental Health teams, care home workers and community groups) in end-of-life rights – our target for this period had been 85. We have also provided end of life rights training to other organisations including the Older Peoples’ Advocacy Alliance (OPAAL) through this project.

Academic research finds that care professionals often carry information about patients ‘in their heads’ rather than relying on recorded notes to support the transfer of information between staff across organisational boundaries.\textsuperscript{27,28,29} Many dying patients do not want to discuss their end-of-life and will avoid negative information\textsuperscript{30} and the recent VOICES survey of bereaved relatives and carers loved ones found that a minority (32%) of patients knew they were going to die.\textsuperscript{31} So whilst some patients resist confronting their end-of-life, it is also clear that some healthcare professionals are not telling patients that they are dying, thus reducing the chances of effective planning and exercising their rights under the MCA in relation to decision making about medical treatment.

\textsuperscript{26} Sue Wilkinson (2013), An Analysis of Calls to the Compassion in Dying End-of-Life Rights Information Line: Unpublished.

\textsuperscript{27} Cox K et al (2011) Is it recorded in the notes: Documentation of end-of-life care and preferred place to die discussions in the final weeks of life \textit{BMC Palliative Care} 10(18) doi:10.1186/1472-684X-10-18


\textsuperscript{29} Paget A, Wood C (2013) Ways and Means Demos/Sue Ryder

\textsuperscript{30} Barnes KA et al (2011) Advance care planning discussion in advance cancer: analysis of dialogues between patients and care planning mediators \textit{Palliative and Supportive Care} 9(1): 73-79

\textsuperscript{31} First national VOICES survey of bereaved people: key findings report (2012) Department of Health

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
5. Is the Act widely known and understood by those who are directly affected by it and by their non-professional carers? To what extent does the Act provide protection and reassurance for informal carers? Has the right balance between protection of the carer and protection of the individual lacking capacity?

Surveys indicate that between 3-5% of the ‘well’ general population have an Advance Decision (the figure would be similar for numbers with a health and welfare LPA).\[32,33\] This is in stark contrast to the 82% who knew and stated what level of life-prolonging intervention they would want. 53% wrongly believe that they had a legal right to make end-of-life treatment decisions on behalf of their next of kin.\[19\] With these figures in mind it is safe to say that the refusal of life-prolonging treatment element of the Act is not well known and people are not acting on their rights. The figure is somewhat better for those who are dying, with 18% having their medical treatment and care preferences formally recorded (e.g. through the use of an Advance Decision or recorded with their medical records).\[34\] However, qualitative research of terminally ill patients indicates that there is widespread ignorance and misunderstanding about the aims and legal validity of Advance Decisions amongst this group.\[35\]

Compassion in Dying’s Information Line receives approximately 200 calls a month (plus letters and emails) from people requesting Advance Decisions, wanting to gain clarity over what their end-of-life rights are, raising concerns with the efficacy of Advance Decisions, how to word their wishes, concerns about doctors signing them and queries about LPAs etc. Callers are typically information seekers, want to plan for their end of life, are aged 65 and older and have found out about the Information Line through the media, Dignity in Dying,\[36\] referrals from charities and sometimes care professionals.

An independent academic analysis of over 200 calls to the Information Line found that 25% of callers reported not understanding the law as a barrier to writing an Advance Decision.\[37\]

\[My mum and brother took out Living Wills [in the 1990s]. But I thought this sort of thing had vanished with the onset of these uhm, you know, with the Power of Attorney thing, is it?\]

\[My wife’s had one of these sort of Living Wills and of course it was updated in 1999. … And it’s no longer acceptable in these homes. She had to go into a home and they don’t recognize that. They’re talking about one of these ones with a red border [‘Do Not Attempt Resuscitation’ Order].\]

\[\[32\] YouGov (2011)\]

\[\[33\] BSA (2013)\]

\[\[34\] YouGov (2013)\]

\[\[35\] Shale S (2012) How do people approach decision making at end of life? A secondary analysis of narrative interviews with patients about experiences of living with terminal illness Compassion in Dying\]

\[\[36\] Compassion in Dying is the charity partner of Dignity in Dying.\]

\[\[37\] Sue Wilkinson (2013), An Analysis of Calls to the Compassion in Dying End-of-Life Rights Information Line: Unpublished.\]
Compassion in Dying – Written evidence

Is it [an Advance Decision] rather like a Power of Attorney type of thing that gives you the ability to act on their behalf?

He [solicitor] mentioned Lasting-, I hope I’ve got this right, a Lasting or Continuing Power of Attorney … And of course I’ve got the Living Will. I just wondered if you could- I mean are they the same? Is there a subtle difference?

In the summer of 2012 Saga magazine published a letter which detailed what Advance Decisions are and gave the Information Line number. This resulted in a large spike in calls (1,500 over two months). Many callers had said they had thought about the issue but didn’t know what to do or who to contact for further information.

The reach of the Information Line goes beyond just those people who contact it. About a third of calls are on behalf of two or more people, and around a quarter of the callers who request an Advance Decision information pack ask for multiple packs to be sent. It is possible that for every 100 calls, around 130 – 140 people are actually reached.

This all indicates that with the right promotion, many people would be able act on their rights. This work should go beyond articles in the media and encompass a dedicated programme of health promotion work led, for example by Public Health England and key stakeholders such as Compassion in Dying, Age UK, and Alzheimer’s Society etc. Without considered promotion of end of life rights the public is reliant on either just ‘knowing’ about Advance Decisions and LPAs, word of mouth or reading about them in newspapers.

6. Has the Act ushered in the expected, or any, change in the culture of care?

It is hard to tell if there is a direct link between change caused by the Act and change as a result of initiatives such as ‘no decision about me without me’, the ‘Find your 1%' campaign targeted at GPs38 and the End of Life Care Strategy etc. The principles of the Act appear to be embedded within these; however understanding of Advance Decisions etc by care professionals and the time needed to engage with patients about these issues can be limited.

Culture change won’t happen overnight. Recent research by Demos/Sue Ryder indicated that there is a prevailing scepticism about the progress made in stimulating public discussion of dying, and recommended attention should focus on generalist training in end-of-life care and rights39 (with investment in professional training) alongside more general public awareness.

7. Is there any evidence that the provisions of the MCA affect some groups disproportionately? If so, what data exists to compare representation across different socio-economic groups, Black and Minority Ethnic groups, and gender?

Over 90% of people who contact our Information Line are ‘white British’ so it is vital that BME groups are reached. Initial findings from our ends of life rights advocacy project in east London indicate that additional work needs to be done to ensure that BME communities are made aware of their end-of-life rights appropriately.

38 http://dyingmatters.org/gp


In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Decision making

8. Are those directly affected by the Act being enabled and supported to make decisions for themselves to a greater or lesser extent than they would have been in the past? Does the means by which the decision is made – ‘general authority’, Lasting Power of Attorney, deputyship, Court of Protection – affect the quality of decision making?

With limited data available on numbers who have an Advance Decision or have appointed an LPA it is difficult to say whether more people have acted on their end-of-life rights now than before the MCA came into force. We would encourage research to examine this.

9. What evidence is there that advance decisions to refuse treatment are being made and followed?

There is very little in the way of evidence on the numbers of Advance Decisions being made. As indicated in Q 7, 3-5% of the general population have made an Advance Decision and 18% of dying people had their medical treatment wishes recorded. As far as we are aware there is no published research that examines whether Advance Decisions are being adhered to or not. Findings from a Freedom of Information Act request we conducted with Ambulance Trusts in 2011 indicated that half of the Trusts held data on the numbers of people with an Advance Decision registered with them. However, only one Trust was able to supply this information and none could supply information on adherence.

Research is urgently needed to explore numbers who have an Advance Decision and reasons why the numbers are (potentially) low. There is a small body of research literature on the effectiveness of Advance Care Planning more broadly (which can include an Advance Decision element).

There have been several high-profile news stories around advance refusal of treatments. A man with Motor Neurone Disease, whose Advance Decision was contested by his care team, had his wish to refuse life-prolonging treatment upheld by the Court of Protection. A man with Down’s Syndrome challenged a hospital’s decision to issue a DNAR order without his and his family’s knowledge, giving his disability as one of the reasons. Both stories demonstrate an extremely worrying lack of understanding of the MCA by some care professionals, and therefore a need for MCA and end-of-life rights training. It seems unlikely that these cases - which directly contravene the principles of the MCA – are exceptional: what limited evidence there is suggests that MCA principles are well reflected in professional guidance and but that there is still some way to go in embedding them in practice.

The Court of Protection and the Office of the Public Guardian

10. What has been the impact of the introduction of Lasting Powers of Attorney (LPA), especially with regard to decision making on matters of personal care and welfare?

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40 http://www.dailymail.co.uk/news/article-2138070/Motor-neurone-sufferer-wins-right-die-living-blinking-eye.html

41 http://www.bbc.co.uk/news/health-19570364

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Calls to our Information Line indicate that there is confusion between LPAs and Advance Decisions, which indicates that promotional work is needed to clarify this difference to both the public and care professionals. People may decide not appoint an LPA because of the level of fees and some callers to our Information Line find filling the form in very difficult (as a result they may seek expensive legal advice). The numbers of people with an LPA are available from the OPG, however data does not seem to reflect the actual numbers of living people with an LPA or how many having lost capacity had their LPA recognised.

11. What concerns, if any, are there regarding the costs associated with registering an LPA, or with making an application to the Court of Protection?

People should not be required to incur anything other than minimal costs in order to exercise their legal rights. We are absolutely clear that LPAs are not merely about the exercise of choice but concern the exercise of rights – the right to refuse medical treatment. Compassion in Dying takes numerous phone calls each year from people seeking advice on completing LPA forms. Callers tell us that multiple fees (if you have to re-submit due to errors on the forms etc.) act as a deterrent and often push people needlessly into taking expensive legal advice. This all acts as a deterrent and puts people off appointing an LPA. However, the new online version of the LPA should go some way to reduce the amount of re-submissions. We also note that the Office of the Public Guardian has plans in place to reduce its fees for registering an LPA and to reduce the time taken to process applications, which may go some way to reduce current barriers to people wishing to make an LPA.

22 July 2013
In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Dear all

1. I am grateful for the chance to be able to respond to your call for evidence and especially wanted to respond to this important subject on this vital piece of law that has the potential to make life’s better and create greater protection again the vulnerable and those unable to speak up for themselves the protection in law to not be taken advantage.

2. Before I get into detail please allow me to give some background and context of why this important subject to me.

3. Hi my name is Simon cramp and I am 42 years old and I have a learning disability and dyslexic and dyspraxia and have had these lifelong for as long I was live. So why I am interested in this. well a lot has happen since the original law was passed by parliament in April 2007 as it was two years after it was acted as mental capacity act 2005 and have read though the green paper who decides and then the white paper making decisions and when it was published as a draft bill the mental incapacity act in 2002 or 2003 I believe sorry cart remember the exact date. I felt I need to response to the joint committee that was set up by parliament of both houses and chair by the late lord carter. and was then after submit evidence was called for oral evidence and my mum who is no long with us was dead excited to see me on telly her son give his views and arguing his case to the committee at what changes he want to see . I am so proud as someone that had a learning disability to be able to have a great discussion and informed I believe that I am only one of four people with this disability to appear in front of this committee and have the argument that was I believe very powerful to influence their decisions in the reconditions they made to parliament and government.

4. I got the name originally give to the bill changed and me and colleagues got advocacy which is not at the time feature in the bill as statutory but is in the original mental health act 1983 and then that was succeed as the mental health 2007 . A very proud day

5. A coupled with this also to tell you about me I am a member of the royal society of medience intetetual disability forum and have been since 2007 as we look at issues to do with learning disability and have been a fellow of the centre for welfare reform www.centreforwelfarereform.org and want a fair deal for people with learning disability and finally I speaking from the perspective of someone who user services but as I said earlier in the latter stages of the policy and the parliamentary process of it going thought the house was heavily involved by campaigning and getting my point across to what I feel I need to get across .

6. I am sorry for the long introduction but I feel it important from where I am coming from on this important subject

7. Now to pick up your important questions and I may not answer all them

8. Overview and context

1. To what extent has the Mental Capacity Act 2005 (MCA) achieved its aims?
It limited I believe it like if I can suggest the original learning disability policy by the then labour government valuing people which after nine year people didn’t know it existed .and it a problem . and after the great fan fair apart from court cases you hear very little in the media or online unless it say a book entitled 1.Law, Values and Practice in Mental Health Nursing: A Handbook

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see link  http://mcgraw-hill.co.uk/html/0335245013.html, the book talks about the mental capacity act but is a great foil for the main code of practice and it give it in very simple language and is done by who I believe one of the great practitioners and expect on policy in this area toby Williamson, it really not something that gets the publicity and my moan is why is everything online it a disgrace and doesn’t help people to be aware of the act. And those who find filling in forms difficult online. And it codes of practice. Are not used and my question would be who has read the code of practice outside of the professional circle. Because they are big documents with lots of detail and perhaps the key areas of the act that are used most should be a pocket book that is issued at the government expense in hard copy. Cards that are based on last power of attorney the bases on the principles on the act itself and some simple point or bullet point what their legal reasonability is.

9. Question Which areas of the Act, if any, require amendment; and how?

10. There need to be another publicity campaign and also it need to relate to the draft consumer bill you can find it at https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/206367/bis-19-925-draft-consumer-rights-bill.pdf, currently just finished it consultation process because companies are taking and angle and not be responsible re the sect by saying if there a dispute between a client and the person who is helping them in a from all way or informal way re say a miss sold phone contract because the company is suggesting that they believe that the person under the act has quite from the company “he I believe stood the contract when in fact especially someone with a learning disability has not fulling understood all the implications that that contact entitles”

11. Question At the core of the MCA are its principles and definitions of capacity and best interests. Are these appropriate?

12. Yes but need updating and reflecting the country we live in perhaps a section that deals more specific to adult social care. also need to reflect the policy ideas and aspiration re individual budgets The 6 key prinpanals in Dr Simon Duffy book keys to citizenship THIS IS BRIEF OVERVIEW

13. Author: Simon Duffy

14. Keys to Citizenship is now published by The Centre for Welfare Reform.

15. This is the Second and Enlarged Edition of Keys to Citizenship with a new chapter on Self-Directed Support.

16. Keys to Citizenship is a guide to getting good support for people with learning disabilities. It is an intensely practical book full of examples, information, tips and hints.

17. Duffy split it in to 6 key areas and has change on of them but the six areas of prinpanal the book is

2. Direction                                             4. Support
5. Money                                                6. Community life

19. And the last area has been changed to freedom and I will briefly describe what the paper is aim at here is the link to get a copy http://www.centreforwelfarereform.org/library/by-date/keys-
Simon Cramp – Written evidence

to-citizenship.html but the keys to Citizenship book by Simon Duffy tried to argue that having a marriage a sexual relationship or mortgage for a home we should change this and if this don’t happen then the act is a waste of space for those who want to have these basis rights. I want to quote briefly to highlight the power of this book and what I believe should be achieved.

20. On page 9 under how to get self-determination without representation

21. “It is sometimes assumed, wrongly that just because someone has a learning difficulty they need someone like a guardian to represent them. This is not true in the different countries that make up the United Kingdom. I fact it is rather the law will assume that you are capable, that you have the same rights as everybody else, until someone proves that you are mentally incapable.”

22. And it lots of example of how these are and perhaps not use lawyers. He just very clear for ordinary people to see.

23. And recently a paper by the centre for welfare reform on freedom which explores the 6 key areas but also a 7 freedom so you can take risks you will fine at freedom

24. Author: Simon Duffy

25. Too often people with learning disabilities find that they can only get support by losing their freedom. But good support is about enhancing and supporting freedom. In the first of our new practical guides we give advice on supporting people to be free.

26. And the freedom paper builds on that area he changed re freedom is important and reinforces what keys to citizenship

27. Implementation

Question To what extent have the five principles of the MCA been implemented in frontline practice? What evidence is available to assess this? Is there a satisfactory balance between enablement and protection?

28. Answer. No because frontline staff are simply scared of doing something wrong

29. Question How effective was the Government’s implementation plan? What measures were taken to ensure that professionals and families of those who lack capacity know about and act in accordance with the provisions of the MCA? Has it led to sustainable change?

30. Answer No because they are bother about other useless stuff and wrecking the public sector and don’t have a plan to move the country in the right direction as they are hitting the very people this act was there to protect or help by hitting them with cuts and more cuts and tighter criteria

31. Question Is the Act widely known and understood by professionals

32. Answer No because it simple there would not be as many court cases especially at the court of protection

33. At the core of the MCA are its principles and definitions of capacity and best interests. Are these appropriate?

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
34. Question Has the Act ushered in the expected, or any, change in the culture of care

35. Answer No because we have had scandals like winterbourne where people have been convinced and then the sentences were a joke

36. **Decision making**

37. Are those directly affected by the Act being enabled and supported to make decisions for themselves to a greater or lesser extent than they would have been in the past? Does a the mean by which the decision is made – ‘general authority’, Lasting Power of Attorney, deputyship, Court of Protection – affect the quality of decision making?

38. I think if I may again quoting for an interesting paper again from the centre for welfare reform The Relational Basis of Empowerment by Karl Nunkosing and Mark Haydon –Laurelut editors John oBrien and Simon Duffy the need for roots the four Service Cultures which is on page 22 footnote 4

39. What evidence is there that advance decisions to refuse treatment are being made and followed?

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
40. Has the MCA fostered appropriate involvement of carers and families in decision-making?

41. No

42. Question Has the role of the Independent Mental Capacity Advocate (IMCA) succeeded in providing a voice for clients and an additional safeguard against abuse and exploitation for those who have no-one to speak on their behalf?

43. Answer No for the reason I give in a later question

44. Has the level of referrals to IMCAs met expectations? What are the reasons for the regional variations in the number of referrals?

45. Don’t know

46. Question Are IMCAs adequately resourced and skilled to assist in supported or substituted decision making for people lacking capacity?

47. Answer doesn’t know seem to have falling of the radar since the big fan fair at the time of the act being implemented

48. Deprivation of Liberty Safeguards

Are the safeguards in the Deprivation of Liberty Safeguards (DoLS) adequate?

49. No because it not be made a fan fair it a specialist area that the government only address after the bournwood gap judgement in the European court

50. Are the processes for authorisation, review and challenge of DoLS sufficiently clear, accessible and timely?

51. Clearly not as the government had to make emerancy legistration regarding registration and blame it on the other political parties it plan wrong to use things in this area a political football

52. The Court of Protection and the Office of the Public Guardian

Question Are the Court of Protection and the Office of the Public Guardian sufficiently understood and accessible to all? Are they operating effectively and successfully?

53. Answer No as I said earlier in the submission it a joke that everything has to be fill in online as in my book if you have a disability and struggle to write this in a way that is easier for you. Then the issues about it more accessible online is laughable it about government saving money which is not what the prinpalables is about this act it about giving people choice.

54. What has been the impact of the introduction of Lasting Powers of Attorney (LPA), especially with regard to decision making on matters of personal care and welfare?

55. Answer Winterbourne is a classic example of where it failed miserably.

56. What concerns, if any, are there regarding the costs associated with registering an LPA, or with making an application to the Court of Protection?

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Simon Cramp – Written evidence

Will become a place less accessible because people will be unable to afford the fees and everything online as this current government has this stupid idea that everyone i.t literate

57. Question is legal aid available and sufficient? What impact will the recent and proposed reforms to legal aid have?

58. Answer No because of this government misunderstanding for service user it completely take the option of the table for welfare and other social care issues and I suspect under the legal aid and sentencing act 2012 will stop most claim for the simple fact of the state saving money. To my mind it a joke and insult to the vulnerable and those on low incomes

59. Hi I hope I have given you a flavour of what I feel on this important subject

Please see links attached.


Submission given by

Simon Cramp
29 September 2013

References

1. Law Values and Practice in Mental Health Nursing a Handbook by Toby Williamson & Rowena Daw

2. Keys to Citizenship A guide to getting good support for people with learning disabilities re print 2006


4. The Relational Basis of Empowerment Karl Nunkoosing and Mark Haydon –lurelut july 2013
DBM – Written evidence

Mental Capacity Act 2005 – Is It Working?

Submission of Evidence:

Re: Society’s Most Vulnerable - Mental Health Patients

We read recent newspaper reports of the draft changes to be published shortly with a mixture of expectation and disappointment. Very little about mental health issues beyond judgement secrecy.

In the last year and a half, due to our personal experiences as parents of a mental health patient, we have formed very strong views of obvious changes needed in the administration of mental health patients by integrated mental health trusts around the country, in the best interests of the patient.

These would impact upon social workers seconded to the trust, and also on the trust and its staff. The changes are not rocket science, they are not revolutionary and they are not contentious. They are simple, good common sense.

1. A trust should not be allowed to ask the local council to raise a secret Safeguarding alert on a person who has filed a substantial criticism of the trust in the Court of Protection. In our case the alert was raised the day after the manual of evidence was served on the trust by us. Special independent and impartial arrangements should be made for these Safeguarding alerts.

2. Interviews and meetings which can alter the freedoms and rights enjoyed by the patient and family must be recorded, as in our police forces. Transcripts of these recordings must be made available to those present when requested. Challenges to the transcript must be allowed to ensure they conform to the recording. We have obtained substantially false meeting minutes in our case.

3. Approaches to the Court of Protection by the local council for lack of capacity, at the request of the trust, without the trust being joined as a party must be banned. In what other court in the world is the “accused” not able to question their accuser? This is a denial of a fundamental human right in any judicial system. At present, families and legal representatives of the patient cannot ask questions in court about diagnosis, medication and care plans because the local council states, as in our case, those questions should be directed to the absent trust. They are fundamental in our case, and others.

4. Local councils must be banned from applying to the Court of Protection under a name, other than their own and later claiming the application is from the local council. They must be banned from applying in the name of the trust such as “Rehabilitation and Complex Needs”, but later claim the local council is the applicant, as happened in our case.

5. Obstruction by a trust of the release of Medical records for an independent second opinion diagnosis for months and months must be banned. A court order should not be required for this.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
6. Trusts should not be allowed to retrospectively assess a patient’s capacity to instruct a solicitor, to obtain medical records to challenge the trust. In our case, two assessments in quick succession, with different staff were needed to remove our daughter’s solicitor of 10 weeks standing. The medication challenge was in progress for 7 weeks. We believe it to be a fundamental principal that it should be beyond the powers of a trust or local council to retrospectively remove a patient’s solicitor and therefore their access to the courts. Special independent and impartial arrangements should be put in place for such a fundamental assessment of capacity which would deny a fundamental right.

The Court of Protection ignores, without penalty to the trust or local council:

a). Submission of “evidence”, such as their unsigned letters which are clearly fraudulent, when the actual signed letter is also presented to court in evidence, with different content;

b). Claims of the existence of a document used for a Safeguarding alert, without producing it, with a different content to the actual document submitted to court by the patient’s family;

c). Claims by a trust in written evidence that their trust’s internal second opinion psychiatrist’s report, also in written evidence, supports the position of the trust and local council. When in fact it discounts the trust’s diagnosis out of hand and states, “there is no sign of it”.

With no heavy penalties for this false evidence, the trust and local council are unrestrained by the inaccuracies of their evidence submitted to the Court of Protection and the court is overwhelmed.

The artificial barrier between Property and Affairs applications and those for Welfare create a situation where the trust and local council are never in the court together in the same application. They act as one party in their planning and actions which control the patient and provide evidence.

The original concept of the integrated mental health trust was focused on the benefits it brings to the patient:
1). Single assessment at point of entry of a patient into the local system to access any service.
2). Ongoing contact with social workers whilst in the system.
3). Smooth takeover by social services at the point of release back to the community.

The previous problems of “discovering” discharged patients months later in the community should now be a thing of the past. We can expect more integrated mental health trusts and more problems.

Our experience with one of the first integrated trusts in the country is that they use the system to their advantage, both financially and otherwise, against the best interests of the patient in our case.

We will have our third hearing sometime in September at the High Court, Strand when our hard won independent second opinion is presented by an eminent psychiatrist, seven months late.

We believe what we have uncovered is also happening in other trusts around the country, particularly when the trust perceives a potential financial threat from the patient’s family due the trust’s negligence. We only ever wanted the correct diagnosis and treatment for our daughter.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
There appear to be automatic and illegal Trust protection actions implemented immediately. We had experience of the local mental health service for our daughter from 1997 to 2003 and the changes we see have drastically limited the types of accommodation and treatments offered. There is reliance upon over medication with drugs such as Clozapine and Quetiapine even for a diagnosis of Bipolar. Attempts are made to change diagnoses to fit the required medication, to justify preferred residential accommodation.

Prior to the Act, successful rehabilitations occurred using mostly psychotherapy groups and one to one sessions, with the psychiatrist sometimes sitting in to gather information. Now the psychiatrists do not see the patient themselves, but act through trainees and group meeting only.

Powers conferred to protect the patient are continually used against the patients’ interests. Assessments of capacity are carried out instantly in units by the care team themselves to justify their own actions. These are repeated to change the lack of capacity at the care team’s daily wishes. Assessments of Capacity by the Care Team treating the patient are abused and these should be banned. Only independent Assessments of Capacity should be permitted.

Once our case is over, a quick look through the Trust’s Court evidence in connection with the Assessments of Capacity they carried out will convince law makers that internal Assessments of Capacity must cease.

Overview and Context

2. The Act needs to be amended to implement the above common sense protections.

Implementation

7. The Act provides no protection for family carers or the patient, from a Trust’s actions which result from the abuse of their powers when that Trust feels under financial threat due to their negligence.

8. The Culture of Care has changed dramatically since the Act. We have found that an excellent and effective service has been replaced by Trust management with closed minds and fierce protection of authority cloaked in secrecy, protected by a complete misuse of the essential rules of confidentiality. The Act has created integrated mental health services which appear to be beyond the reach of the COP authority and they act accordingly, with impunity and against the best interest of the patient.

Decision Making

12. Neither we nor our daughter have ever had a copy of a Care Plan and decisions made by management and the care team are only ever revealed when actions are taken on those decisions. Opposition to this culture is met by hostility and this same complaint is made by other parents and partners.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
13. As parents, we requested a MIND advocate for our daughter and even though this was the manager of the local MIND advocate service, he only ever voiced the Trust position other than for minor issues. We have therefore questioned if there is a financial issue guiding his position.

**DOL Safeguards**

16/17 The Trust threatened a DOL against our daughter in their case report if their supervised visitation arrangements for her partner were breached by HIM! That document is also in our Court evidence.

2 September 2013

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Our response is informed by our personal experiences and those shared by other family carers who like us have a son or daughter with intellectual disabilities.

1. The MCA has only achieved its aims in a limited way. We have observed that it is often ignored by professionals and responsible authorities and organisations. When implemented it is often poorly done because it is not well understood. The principle that the decision is to be made endeavouring to understand what would work for the individual concerned in a way that they would wish, is often ignored because of financial imperatives or a failure to take a person centred approach. Both ignorance and pressure of work have a part to play in this. All too often families and carers who know the person well are not consulted and therefore excluded from the decision making process. It is not understood that capacity has to be assessed as it relates to the specific matter under consideration. Often a ‘blanket’ or general view is taken about an individual’s capacity to be involved in any decision making process.

2. We are personally aware of two cases where DoLS has been used perversely in order to prevent a parent from having contact with their son. In both cases the respective LAs, who had seemingly been supporting the misguided views of a care provider, were challenged by a solicitor and both were forced to reverse their decisions and apologise. You will be aware of the Neary case and hopefully law firms who work in this arena will be providing further evidence. We are also aware of another case which involved an employee of a LA posing as an individual’s deputy for welfare in order to circumvent the requirements of the MCA.

3. We have personally observed a clash of cultures and beliefs because of polarised views about the use of the MCA v the use of the MHA. Our son was informally admitted to an NHS unit which sought, as far as possible, to use the MCA and a number of patients were admitted using Best Interests criteria. A change in leadership involving both the Neuropsychiatrist and the Clinical Psychologist resulted in a number of patients status being altered in that they were detained instead under the MHA. This seems to be particularly problematic where LD services fail to employ an interdisciplinary approach and the more traditional mental health model holds sway.

4. In more general terms we have found the Act to be poorly understood by health and social care professionals. There is a lack of awareness of responsibilities and this is reinforced by a lack of accountability. Our son was significantly damaged as a result of being abandoned in an NHS service which was inappropriate and also, on two separate occasions, identified as allegedly abusive. That alleged abuse was confirmed in one case and the other is under investigation. This was in spite of a Best Interests meeting which clearly identified how his needs should be met. We had to go to law to remedy the situation. Independent advocacy was unhelpful because those organisations are usually directly dependent upon the responsible agencies for funding with no independent financial support available. This does not encourage an entirely unfettered approach to the support available and advice offered. An independent nationally organised and monitored system is needed.

5. The financial sector also lacks understanding of the Act and the role of deputies.
6. The frequent failure of the relevant authorities to act in the best interests of so many individuals would seem to indicate that better protection would be offered by a carefully selected individual Deputy for Welfare. All too often families have to seek the support of charities such as Mencap or go to law which is, because of changes to the legal aid system seemingly becoming more difficult.

7. The recent reforms to legal aid are unhelpful and likely to mean that those most vulnerable people, like our son will be too readily be consigned to existing in utterly impoverished circumstances amounting to a sanitised version of the Eastern European care we so willingly, vociferously and quite rightly condemn.

8. The process of applying to become a Deputy is somewhat arcane and represents a significant cost, especially if help is needed from a solicitor. Better guidance and support would be helpful as the process is somewhat daunting.

9. Greater regulation which ensures that there is accountability and that penalties apply is essential.

10. The CQC and other regulatory bodied should have powers which ensure that action can be taken to ensure corporate accountability. We have recently received the results of an investigation into the deliberate and unjustifiable withholding of support which made it difficult to achieve an agreed outcome for our son in line with a Best Interests decision. It is apparent from that report that professionals were pressurised to ignore the ethical requirements and guidance of their professional bodies. There was insufficient oversight of the mangers concerned who were presumably endeavouring to comply with possibly inappropriate corporate policies. Sadly, the overall manager of the service departed before completion of the investigation instigated as a result of our complaint. That individual will be free to continue to work in LD services elsewhere and that is most regrettable. A lack of transparency results in NHS Trusts and LAs never being either exposed or effectively held to account.

11. It is abundantly clear that The NHS is process and protocol focussed with the emphasis on throughput as the measure of success rather than outcomes. In the case of difficult to define and measure outcomes when considering individuals who have an intellectual disability the situation is much worse. LAs seem to be even more difficult to hold to account and rarely, if ever seek to measure real outcomes as they apply to individuals who lack capacity and have no voice.

12. Human rights and the law with regard to discrimination are seemingly ignored. It is extremely unlikely that there is any awareness of the UN CRPD in the LD services of either the NHS or the LAs.

13. Assessment and Treatment Units have a very poor record with regard to ‘treatment’ where intellectually disabled individuals who have no diagnosed mental illness are concerned. Such individuals are usually in need of skilled support in services that recognise the often complex nature of their disability and are able to respond to the issues identified in the course of the assessment process. It is not at all unusual for social services, in the form of a care manager, probably because of funding being withheld, to ignore the findings of an assessment undertaken by the ATU. Best Interests decisions be they formally stated, present in evidence based recommendations, or obvious by inference are simply ignored.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
We and other families have experienced such responses and our sons and daughters have, as a result, suffered poor support and treatment and often abuse and neglect in inappropriate placements. Inadequately trained, poorly led, poorly paid and often entirely unsuitable frontline staff are employed. Abusive cultures rapidly develop and if (rather than when) the abuse comes to light only front line staff are punished. Commissioners, care managers, social workers and other professionals who were aware of the glaringly obvious deficiencies of the provision remain in post and continue to repeat the same mistakes. Some sort of corporate accountability is required. Identified needs even when backed by a Best Interests decision are ignored with impunity. The eventual final outcome for the individual is that they are declared to be treatment resistant and consigned to a secure service. The MHA, MCA, human rights legislation and protocols and anti-discrimination legislation, all of which should protect the most vulnerable in society are seemingly all too often ignored until families complain and seek resolution through legal action.

3 September 2013
Dementia UK – Admiral Nurses – Written evidence

These comments are collective of several Admiral Nurses:

It is difficult to answer all the questions individually so we have grouped Admiral Nurses responses into themes; we are not aware of any published evaluation or reviews of the MCA and its application and outcomes other than the work of Professor Jill Manthorpe.

Admiral Nurses report some positive examples of professionals using the Mental Capacity Act but sadly mostly it is very poor and ill informed.

Admiral Nurses report a perception that the MCA is legislation that is applied in a variable and subjective way and therefore despite various case law examples, see much anxiety and misinterpretation in professionals in using the MCA in practice.

Generally the MCA (2005) offers a common sense approach to protecting the vulnerable, but is not necessarily understood by all with regards to its implementation.

Vulnerable people are essentially better supported in making decisions if the MCA is appropriately used. There is also better use of safeguarding procedures to protect individuals at risk. The MCA provides the legal framework for those considered vulnerable, which can be limiting in interpreting acts of abuse.

Largely the MCA appears to have been embraced by health and social professionals and efforts made to understand it, but there are still inconsistencies with its implementation, and it is often poorly understood in practice and public alike (see example in box 1).

The need for ongoing assessment of capacity needs to be reinforced; it is not just a ‘one off’ assessment.

Teaching has been made available in some areas though consultation with Admiral Nurses across the country indicates there being huge variability in this. The MCA is complex and open to interpretation so information about MCA needs to be more accessible and user friendly. Training also needs to be repeated and include case examples that are ‘real’ to practitioners of both Health and Social care. More advice/guidance is needed on the relevance of MCA to people in the community and its application in people’s own homes. However some nurses report a lack of resourcing in training around the MCA which leads to omissions in its use and poor practice.

Carers/families are not always involved in or informed about best interest assessments, although this is improving. Increased awareness amongst professionals of the benefits of including carers is still needed. Generally MCA processes and procedures are poorly understood, so are not implemented robustly.

Access to advocates is variable and the procedures for accessing advocates are not always clear or the need for them understood.

There are some very poor quality capacity assessments being carried out and I still see the words patient lacks capacity in documentation with no reference to the context of the assessment on indeed the purpose of the assessment. I have seen decisions made when PWD lacks capacity without involvement of OIP so arguably these are not BI decisions.

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Dementia UK – Admiral Nurses – Written evidence

Despite having BIA’s for DoLs and AMHP’s for MH Act it feels that there should be a specialist role within the MCA to ensure specialist knowledge and some standardisation in its implementation particularly so that more complex decision making processes can be embedded in practice.

Box 1:

Case example of misinterpretation:

Patient in residential care following emergency admission due to a fall, issues around fall resolved and patient wanted to go home.

GP - Patient has MMSE of 23 so should stay in care. They have dementia.

Admiral Nurse - Have you assessed patient’s capacity?

GP - Yes I have done MMSE.

Admiral Nurse – that is not a measurement of capacity, you should do a capacity assessment.

GP – It doesn’t apply to the patient as they are self-funding.

Admiral Nurse - This legislation doesn’t discriminate in that manner etc. (Advised on what should be assessed and how.)

GP - Looks like I should go and see the patient.

This patient was assessed as having capacity and is now at home with carers three times a day.

30 August 2013
I write to inform you of the details of a new steering group my Department has established on the Mental Capacity Act 2005. The work of the steering group will include consideration of Deprivation of Liberty Safeguards.

In the Department's written evidence to your Committee in September 2013, we expressed the Government's belief that although the implementation programme put in place following the enactment of the Mental Capacity Act led to important steps forward in changing cultures to embed the Act, practice everywhere in the country does not fully meet the ambitions and expectations of the Act. As such, our intention is to work with national partners to assess progress in implementing the Act and decide what further action is required.

Furthermore, in the Government's response of October 2013 to the report of the Health Committee of the House of Commons on its post legislative scrutiny of the Mental Health Act 2007, the Department stated its intention to set up a new Mental Capacity Act Steering Group to inform our work in this area.

I am pleased to inform you that this Group held its first meeting on 14 October 2013. For your information, I enclose a copy of the Group's Terms of Reference, and details of its membership.

The ultimate purpose of the Mental Capacity Act Steering Group is "to agree a joint programme of action to continue to implement the Mental Capacity Act and the Deprivation of Liberty Safeguards". The Group is time-limited to 12 months in the first instance, after which members will decide whether it should continue to meet or its work be absorbed into existing programmes.

The insights and recommendations of your Committee will be vital in informing the Government's continuing work on the Mental Capacity Act and Deprivation of Liberty Safeguards. Please accept my thanks in advance for the invaluable work you are conducting in this area. If the Department can be of any assistance to your enquiries please do not hesitate to get in touch.

Norman Lamb
Mental Capacity Act Steering Group (MCA-SG)

Terms of Reference

Context

The Mental Capacity Act 2005 is a very significant piece of empowering legislation which affects some two million people and places responsibilities on people working in health and care settings to assess the capacity of people to make decisions, help them to make those decisions and, if they lack capacity, to take decisions for them in their best interests.

A number of national bodies are responsible for ensuring that the Mental Capacity Act and Deprivation of Liberty Safeguards are embedded in the work of the health and care sectors. Implementing the Mental Capacity Act and Deprivation of Liberty Safeguards are dependent on close, collaborative working between national bodies that are responsible for providing, commissioning, regulating, inspecting and overseeing health and care services and training and educating health and care staff.

This steering group brings together the key national bodies responsible for implementing the Mental Capacity Act and Deprivation of Liberty Safeguards.

Purpose

The ultimate purpose of the MCA-SG is to agree a joint programme of action to continue to implement the Mental Capacity Act and the Deprivation of Liberty Safeguards.

To achieve this purpose the MCA-SG will:

1. Discuss the evidence and share experience to reach a common view on the current state of implementation across the health and care sectors;

2. Decide how to promote understanding of the Mental Capacity Act and the Deprivation of Liberty Safeguards and to share best practice; and

3. Take into account key legal developments or implementation issues which have implications for the way in which the Mental Capacity Act and Deprivation of Liberty Safeguards are applied in the health and care sectors.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Management

The MCA-SG will be managed as a sub group of the DH Mental Health System Board.

The MCA-SG will be a time limited group operating for twelve months, after which time its membership will decide whether it should continue to meet or its work should be absorbed into the work of the Mental Health System Board.

It will meet quarterly.

Representatives will work together outside the quarterly meetings as necessary, to progress actions agreed by the Group.

Member organisations

The MCA-SG will include senior representatives from:

- Department of Health (Chair- Director of Social Care Policy)
- Ministry of Justice
- Office of the Public Guardian
- Court of Protection
- NHS England
- Care Quality Commission
- Local Government Association
- Association of Directors of Adult Social Services
- Health Education England
- Royal College of Psychiatrists
- NHS Confederation
- College of Social Work
- Social Care Institute for Excellence
- Public Health England
- Monitor
- East of England Strategic Clinical Network for Mental Health, Neurology and Disability
- Care Provider Alliance

Links to other boards

The MCA-SG will report to the Mental Health System Board on its discussions and, as appropriate, will raise any key issues to the Board for discussion. It will also update the Learning Disability Programme Board and Dementia Programme Board on its work.

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In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Department of Health – Supplementary written evidence

Thank you for your letter dated 12 November.

I am pleased that you view the establishment of the Mental Capacity Act Steering Group is a welcome development. The Group is very much concerned with trying to establish the evidence of the implementation of the Mental Capacity Act to date and arriving at a plan for improving the situation.

I absolutely agree with you that hearing from service users, families and carers should be at the centre of our efforts to understand the impact of the Act. I have asked officials to set up one or more events to ensure that we talk to a range of people who have direct experience of whether or not the Act is being used successfully. That evidence will be used to influence the work programme of the Steering Group and any subsequent action plan. We will ensure that this is not a one-off exercise but that we continue to consult and engage going forward.

The first meeting of the Steering Group was devoted largely to agreeing the terms of reference and clarifying the role of all the different organisations in implementation. The Group began to identify the areas of concern and gaps in our knowledge. Members were asked to identify what data we need for our analysis, what is available and from what source and what gaps there are and how we might remedy that. This topic will be the main focus of the next meeting arranged for January.

I look forward to meeting the Committee on 3 December.

Norman Lamb

28 November 2013
In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.

Department of Health – Further supplementary written evidence

On Tuesday I undertook to send you and the Committee a note on my views about whether I thought we had filled the "Bournewood gap" with the Deprivation of Liberty Safeguards (DoLS).

The "Bournewood gap" arose from a case where a patient lacked the capacity to consent to being kept at a hospital for assessment and treatment. The European Court of Human Rights found this was an unlawful deprivation of liberty that breached the requirement in Article 5(1) of the European Convention of Human Rights that a person can only be deprived of their liberty, without their consent, in accordance with a prescribed legal procedure. There had also been a contravention of the requirement in article 5(4) that any person deprived of their liberty should be entitled to take proceedings by which the lawfulness of the detention can be decided speedily by a court.

Consequently, the "Bournewood gap" was closed by the introduction of the DoLS in the Mental Capacity Act 2005 (MCA) by the Mental Health Act 2007. The DoLS ensure there is a legal procedure for authorising deprivations of liberty in hospitals and care homes for adults who lack capacity to consent to admission or treatment. DoLS is the framework of procedural safeguards comprising:

- section 4A: a person may be deprived of their liberty under the MCA if this is authorised by an order of the Court of Protection or a DoL authorisation under Schedule A1;
- Schedule A1: the qualifying requirements and process for DoL authorisations to be put in place, and subsequently reviewed; and
- Schedule IA: the circumstances where the MCA (whether by an order of the Court of Protection or a DoL authorisation) cannot be used to deprive a person of their liberty.

The DoLS were designed to address the "Bournewood gap", not just in hospitals, but also in care homes. The Court of Protection is also able to make a welfare order under the MCA to authorise a deprivation of liberty of a person in other settings (if they are not ineligible under Schedule IA), and can determine the lawfulness of any deprivation of liberty under the MCA.

While the gap has been addressed by the legislation, there remain issues of awareness and appropriate use of the DoLS, and I accept that not all care homes and hospitals understand fully when the DoLS should be used. Further work is needed in this area.

An additional issue raised with you was whether there is 'a gap' in relation to possible deprivation of liberty in supported living accommodation. My view is that there is no gap as an application can be made to the Court of Protection to authorise a deprivation of liberty in supported living. We may revisit this in the future, as I said in evidence, as more people with complex needs are cared for in the community. For the moment I am content that local authorities should seek authorisation from the Court of Protection.
Lastly, in cases where a patient has been deprived of their liberty under the Mental Health Act, and medical treatment is required for physical conditions which are not related to the mental disorder, such treatment can be provided under section 5 of the MCA if the patient does not have capacity to consent to the treatment. In a very small number of cases, the treatment required may involve a deprivation of liberty and in such cases the MCA regime is not available because the person is ineligible to be deprived of their liberty under Schedule 1A. However, the High Court has an inherent jurisdiction to authorise a deprivation of liberty for that purpose and therefore there is no gap which requires filling (and in any event, this is not the "gap" that was at issue in the Bournewood case).

You have also asked me to address question 8: The difficulty between providing the appropriate balance between safeguarding and protection has been a consistent theme in the evidence that we have heard. Given the understandable focus on safety within health and social services, how does the Government intend to prevent the empowering ethos of the MCA from continually being overshadowed?

I am very clear that the MCA is very much about the balance of protection and empowerment, and I think all the training and awareness raising and guidance makes this clear. The training invariably starts with the empowering principles – that people are assumed to have capacity; that people can have capacity about some matters and not about others; and importantly that a person must be helped to make a decision before they are found to lack capacity to do so. These are all very important and empowering principles.

As you heard from other witnesses, safeguarding has a longer history and is better established in health and social care. More people understand that their role involves making a safeguarding alert if they are worried about a person, and that there are safeguarding leads who will investigate safeguarding concerns.

We need to ensure that the empowerment message is equally understood. We do this through the guidance we produce; through the messages we give when speaking at conferences, and also through our wider policies on personalisation and choice and control. The empowerment message underpins the response to Winterbourne View; and much of what we are doing to enable people with disabilities to live in the community. It underpins our policies on ‘choice and control’ in both social care and the NHS. We will be writing safeguarding guidance to accompany the safeguarding clauses in the Care Bill, and we will ensure that this balance is present throughout the guidance.

I hope this information is helpful to you and the Committee.

Norman Lamb

9 December 2013
In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Who we are and our connection with the Mental Capacity Act

We are the Derbyshire Deprivation of Liberty Safeguards (DoLS) Team. We are responsible for implementing the Deprivation of Liberty Safeguards within the county and also complete assessments for other authorities who have placed service users in Derbyshire. We are one of the busiest authorities with respect to DoLS in the country and are approaching our 1500th case. The assessors within the team are all Senior Practitioners, who are also responsible for providing non legal advice and guidance on the implementation of the Mental Capacity Act itself to care homes, hospitals, health care professionals and Adult Care Social Services’ teams. We have also adopted a proactive approach in rolling out training sessions to these providers in order to raise awareness of mental capacity assessments, best interests decisions and DoLS.

Overview and Context.

To what extent has the Mental Capacity Act (2005) (MCA) achieved its aims.

The Mental Capacity Act, where it has been correctly used, has been very successful in ensuring that people are facilitated to make their own decisions where they are able to, and in maximising the participation of the service user and consultation of family and carers where they are not. The concept of the least restrictive approach is very useful and the Act assists professionals to balance enablement and protection. The challenge remains to promote the principles and implementation of the Act in a world of diminishing resources, busy carers and professionals, particularly GP’s, who even at very senior levels are reluctant to be the decision maker. Generally, the process is further advanced in social care than in health. The Deprivation of Liberty Safeguards amendment to the Act has led to the scrutiny of the care of thousands of vulnerable people, who would not have come under the Mental Health Act. This has resulted in a much wider implementation of the MCA principles. Service users have been established as having the capacity to make their own decisions, or their participation has been actively promoted, the least restrictive interventions have been arrived at, families and carers have been actively consulted at a much earlier stage, and care arrangements have become more creative, enhancing the life of the individual. We have found that essential to the embedding of MCA/DoLS in every day practice is a proactive approach with the employment of staff at Senior Practitioner level and above to act in an ‘assertive outreach’ role.

What areas of the Act require amendment and how?

The DoLS Code of Practice requires extensive revision. Greater clarity and guidance is required on what constitutes a deprivation of liberty. The Code of Practice is generally perceived by professionals who have to implement it as inadequate and out-dated by subsequent case law. With one judge describing the Deprivation of Liberty Safeguards’ legislation as impenetrable, professionals are faced with what appear to be contradictory judgments, making the assessment of whether an individual enjoys the benefits of the safeguards even more subjective. Without clarity on this issue, the increasing temptation for local authorities is to increasingly restrict the definition of what constitutes a deprivation.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Derbyshire DoLS Team – Written evidence

thereby saving on human and financial resources, but removing the vulnerable person from the protection that the safeguards offer. This complexity and lack of guidance has contributed towards a huge variation in the implementation of DoLS, with many people’s care arrangements remaining unscrutinised and effectively being deprived of their liberty unlawfully.

One of the most helpful ideas in the Act is that of the need for decision-specific mental capacity assessments and best interests decisions. It has promoted a much more accurate assessment of people’s abilities to make decisions that affect their lives, and has empowered the professional seeking to maximise an individual’s participation. Greater clarification and guidance is needed, however, particularly around the distinction between a decision when a formal assessment has to be made, and when carers only need to show that they have had regard for the MCA. The lack of clarity on what this means has resulted in varying interpretations of what it is necessary to comply with the Act. This has resulted in ‘uneven’ assessments by CQC of care homes’ compliance with MCA/DoLS, with many homes failing inspections, but with no idea of how to address it.

Some of the specific responsibilities laid down in the Act need to be more explicit. There are real difficulties with G.P’s refusing to complete mental capacity assessments or best interests decisions, and police or ambulance crew being unwilling to convey persons not covered by the Mental Health Act.

It is one of the great ironies of the legislation that the key concept of proportionality, so useful in acting in a person’s best interests, is completely disregarded by the process of implementation. This is most acutely illustrated by the mandatory DoLS process, with its multiplicity of forms, number of people from different organisations involved in each step and endless repetition of the same information. The process is unnecessarily Byzantine in its complexity, and this, combined with demanding timescales requires a disproportionate amount of human and financial resources, however they are configured; dedicated not to the welfare of the individual but to the maintenance of an administrative edifice. The effect of this over-burdensome process is a perverse incentive not to actively promote MCA/DoLS and to ‘gate-keep’ DoLS referrals; hence the huge variation in the percentage of people coming under the protection of the safeguards. In short, the whole process while laudable in its aims, is barely fit for purpose in this resource-strapped climate and needs drastic pruning.

There is growing confusion over how to proceed with cases where DoLS authorisation after DoLS authorisation is granted. The only recourse is to go to the Court of Protection with its lengthy delays and costs to all parties. The Court is often a disproportionate response, particularly where the only grounds are the continued opposition by the Relevant Person to being where they are. What would be useful is a review panel, similar in function to that operating under the Mental Health Act in which DoLS decisions could be scrutinised. This could take the form of peer reviews, not to re-do the assessments, but to judge their efficacy and appropriateness. This would have the advantage of still retaining scrutiny of care arrangements, whilst reducing the need for costly court interventions. It would also free the Court of Protection’s resources up for complex cases. We are also concerned at the seeming readiness of some IMCA’s and solicitors to take things to court just because they can, with little regard for the merits of the case, any viable alternatives or resulting costs to the person or their carer, who are often themselves cognitively impaired.

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At the core of the MCA are its principles and definitions of capacity and best interests. Are these appropriate?

Whilst it may be difficult to assess capacity, the principles and definitions are widely seen as helpful, as is the guidance given on what constitutes acting in a person's best interests.

Implementation

Our experience is that the embedding of the principles of the MCA is progressing due to extensive input by the local authority, through dedicated training courses and proactive sessions at team meetings across agencies. Willingness to change and adopt the new assessments have been highest amongst the qualified Adult Social Care staff, who have seen them as merely codifying the values and practice that they were already espousing. Less qualified or less confident staff have needed more encouragement to overcome the fear of making a 'wrong' decision. The progress can be measured by increasing prevalence of mental capacity and best interests decisions regarding where a person lives to receive care, management of finances, use of restraint and covert medication. Best interests meetings with families are becoming much more common, and many potential disputes are being identified and resolved earlier without recourse to the Court. The concept of the least restrictive intervention possible is gaining ground and the local authority, along with care home and hospital staff, are beginning to work more creatively with families and carers to facilitate more options within a care package. There have been real difficulties in getting certain sectors, such as health or the police, to engage in the implementation of the act. This shows itself in the lack of DoLS referrals from certain hospitals in the county, inability of care homes to get best interests decision from GP's regarding covert medication, and people having to be (in our view) wrongly detained under the Mental Health Act, because police or ambulance crews are unwilling to convey people under the Mental Capacity Act. Staff across all agencies and at all levels who find the implementation difficult are those who often out of the best of motives take a very paternalistic approach, with the emphasis on protection from physical harm, to the exclusion of enablement, emotional ties and individual choice. In our experience, it is much more difficult to change attitudes than address lack of knowledge; however the prevailing culture in social care is generally moving in the direction of the aims of the Mental Capacity Act.

The Act has highlighted the most complex of cases with a referral for one person leading to the discovery of a carer’s needs. This has been acutely displayed in the cases of people with dementia, being looked after by a partner, who then develops cognitive deficits of their own. Best interests meetings, safeguarding meetings and the DoLS process have, due to the principles in the Act, moved towards a much more balanced approach of protection and enablement, considering how to promote and normalise family/carer relationships as much as possible. We have become very much aware that the perpetrator of harm can often be a vulnerable adult themselves.

Understanding of the Act is limited amongst those who are directly affected by it, until they come into contact with it, but more people are coming under the legislation. Social care staff are becoming more adept at explaining it to the person and their relatives/carers, particularly when completing Mental Capacity Meetings and Best Interests Meetings. The DoLS team engage with the relevant person and those interested in their welfare, and along with the mandatory letters, send out 'easy read' documentation explaining the process and...

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inviting queries. Representatives and any relevant person who is unbefriended or under safeguarding measures and would benefit from it are offered the services of an IMCA.

The high number of mental capacity assessments, best interests decisions and DoLS cases would suggest that the implementation of the MCA/DoLS principles is being embedded in every day practice. This view is supported by the high number of MCA/DoLS queries from all agencies directed at the Senior Practitioner ‘MCA Champions’, whose contact details have been widely promoted. It is one thing to do the assessments, of course, and another to actively engage with the individual in a way that maximises their participation. It is a learning process informed by the growing number of assessments that have been scrutinised by the courts, and these lessons being cascaded down. We would say that the Act has prompted and reminded staff of values and good practice, and made them more explicit. The change in culture is uneven; there are some care homes and hospitals in particular, where ‘matron knows best’, and care arrangements are regimented and institutionalised. These places are slowly being weeded out through a combination of Adult Care social workers and community care workers, DoLS Team, Derbyshire County Council training, contracts team and CQC inspections.

There is no evidence that we are aware of that the provisions of the MCA are affecting some groups disproportionately. All service users’ ethnicity, age, and gender are recorded, so it would be possible to compare those under the MCA, with those receiving services and the population of Derbyshire, as a whole.

Decision Making

The Act has been very effective in promoting decision-making by individuals, who in the past would have been side-lined, particularly in hospital discharge situations. The assumption of capacity, the right to make an ‘unwise decision’ and the competent use of mental capacity assessments have enabled many more people to be supported to go home for longer, against the wishes of professionals, or even family. Where a person is deemed not to have capacity to make a decision, greater attempts have been made than previously to maximise their participation. The DoLS process scrutinises existing mental capacity assessments and best interests decisions; in the vast majority of cases, the outcome of the assessments completed by Adult Care professionals is confirmed. There are complex cases where capacity is hard to determine, or the best interests decision or DoLS authorisation is disputed; these are referred to the Court of Protection. Compared to the number of assessments, these are very few in number. The process of getting a court decision is lengthy and costly, almost invariably involving another round of independent assessments. We have not had a single case where the deprivation of liberty authorisation has been overturned, or a person has been judged to have been placed in care against their best interests.

Advance decisions to refuse treatment are growing in number, but are still very rare. However, the question of whether one exists is being increasingly asked as a matter of course in best interests decisions, and when a person enters into 24 hour care.

Lasting Powers of Attorney are still mainly concerned with finances, rather than health and welfare, (partly due to cost); but where a person has been appointed, their rights in decision making are respected. At the same time, we are checking that the POA is operating by the principles of the MCA, particularly around least restrictive practice.

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One of the successes of the MCA has been to foster much greater involvement of families and carers in decision-making at a much earlier stage. This has unearthed complex and difficult family dynamics, with much greater time and effort being required to reach a decision. Nevertheless, the fruits of this have been much more informed choices, the bringing of families and professionals together, and the resolution of many difficult situations, to all parties’ satisfaction.

The role of the IMCA has been extensively employed by Adult Care, hospitals and the DoLS Team alike when making decisions, and is built into their practices. Within hospitals, there is still greater variation in IMCA involvement, but social workers, when they are involved in cases, are much more likely to either make a referral, or request that the ward do so. Adult Care is much more likely to request an IMCA when placing a person into safeguarding measures; they have been very effective at safeguarding meetings. There is still confusion over what an IMCA’s role is (they are not assessors); but they have effectively enabled the person’s voice to be heard, and have been willing to challenge family and professionals on their behalf. Within Derbyshire, the number of referrals is in line with expectations, and the number of IMCAs and their expertise seems adequate for task. The situation is regularly reviewed.

Regulation

In our view, the role of the CQC is necessary to establish whether the MCA standards are being implemented. We believe that their powers are sufficient and have seen failing homes exposed and turned around following CQC inspections. These positive outcomes have, in our view, been undermined by inconsistent inspections and an unwillingness to engage with homes as to why they are failing to meet MCA standards and how these can be addressed.

29 August 2013
**DGP – Written evidence**

**Summary**

1. As parents of an adult with learning difficulties we believe that the Act has a paralysing effect on medical and social care professionals, preventing them from giving the best possible care to people with learning disability who are assessed as having capacity.

**Facts**

2. The factual background to our submission is as follows. Our daughter is aged 35, the third of our four children. She has Down’s Syndrome, and was born with a congenital heart deformity. She is able to read and write fairly well, and had the insight as a teenager to ask, “Why do I have to have Down’s Syndrome?”

3. Since the age of 22 she has lived independently from the rest of the family in supported accommodation. In the first instance this was 75 miles from home, supported by a private sector provider. About 10 years ago she moved back nearer home to a group house operated by a charitable organisation. Following the financial failure of the latter the local authority considered inviting tenders from private care providers to take over the scheme that included the group home. It decided instead to bring the care and management under the supervision of its own existing local support network. CQC inspections have regularly commended this organisation.

**Health and well-being issues**

4. As others have stated in oral evidence people with Down’s syndrome have difficulties with diet and weight and making healthy eating choices. This is an issue for our daughter. Although her heart defect was repaired some years ago, a cardiac consultant has warned her about the implications of her considerable weight gain. Her weight gain has other health implications: the potential for Type 2 diabetes, and for a stroke. Our daughter’s GP has explained to her the consequences of poor diet and lack of exercise.

5. Various professionals have given our daughter advice and guidance about her diet. She is well able to explain the reasons for making healthy eating choices, and what foods to choose. She does not apply this knowledge personally.

6. Given her weight and health issues the local care services have put in a lot of effort to support our daughter in a variety of exercise activities. It may well be her weight that has led her to drop out of many of these.

**The Act in practice**

7. To their credit the local care managers are well aware of the Mental Capacity Act, and have raised awareness amongst their support staff. However, the way they interpret it in their daily work has a paralysing effect. It is well attested that our daughter has said to a number of staff on particular issues where their advice and suggestions were for her good, “I don’t want to do that, and you can’t make me”. Given this attitude staff and managers have backed off from further intervention.

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8. We have directly asked senior managers what they can do if a service user is judged to have capacity and refuses to follow advice, even if it is in their best interest to do so. Evidently there is nothing effective to be done. They agreed that this has the potential to “throw a spanner in the works” of efficient management of local authority social care.

9. We enquired whether the Association of Directors of Adult Social Services had commissioned research into the extent of this problem—we know of similar situations in SE England—and whether there was any guidance on managing clients who had the capacity to refuse co-operation with social services. Our local authority had no knowledge of such guidance, and our own investigation shows this is an untouched subject.

10. Oral evidence to your Committee shortly before the time of writing expressed the view that caution on the part of social workers led to safeguarding prevailing over empowerment. In cases like that of our daughter the reverse is true. Her empowered decisions to refuse good advice means that her health suffers and will deteriorate significantly. Local care managers have conceded this reluctantly.

11. For our part as parents we have found ourselves somewhat excluded from input into our daughter’s support. Where staff fail to pick debilitating or serious health conditions, (which we have not covered here), it ought not to surprise them that parents react strongly and adversely. Rather than admit the need for change or improvement we have been fended off by the principle of ‘need-to-know’, bolstered by references to the Mental Capacity Act. The line of argument is that things we would rather know are confidential, and our daughter has either not given them permission to disclose, or has sometimes explicitly refused to give it.

12. The bottom line justification for this attitude is that our daughter “has capacity”. This has been asserted by several managers and professionals. Since they pointed us in the direction of the social worker we asked her what she had actually done to carry out the capacity assessment, and what principles she had used. The response was that “it is assumed a person has capacity to make a decision unless it is established they do not and a person is not to be treated as unable to do so unless all practicable steps have been taken to help them”, and, “Professionals involved all currently feel (name) does have capacity to make decisions herself.” We observed that, “We infer from your explanation below that no one has actually carried out a robust and objective issue based capacity assessment for (name)”. The social worker has not rebutted this inference, despite the rather serious implications. The presumption of mental capacity in a blanket way results in staff failing to support where support is needed. There is institutional paralysis.

13. Since our daughter has not cleared the local professionals’ “lack of capacity” hurdle, at no point has it been possible to consider what would be in her best interest. Refusal to do so has been justified by vague reference to the Act.


44 8th October 2013—transcript yet to be published.
Points of difficulty
14. These may be stated in short order:

14.1. People who come across well with their language and social skills may well lead others, professionals included, to take an overly favourable view of their mental capacity.

14.2. Having the mental capacity to make a decision does not automatically confer the insight to understand its consequences.

14.3. Sincere and committed care staff find themselves inhibited from beneficial interventions for people who have, or are presumed to have, mental capacity to make day to day decisions.

14.4. Individuals may be assumed to have mental capacity without anyone making robust and objective issue based capacity assessments for them.

Recommendations
15. Three points merit further action:

15.1. People who work with those whose decision making capacity is in doubt should receive training to understand that determining that a person possesses or lacks mental capacity should not be a once-for-all assessment for every subsequent decision that individual might make. The current Code of Practice is quite clear about this: “A person’s capacity must be assessed specifically in terms of their capacity to make a particular decision at the time it needs to be made.” We do not see this taking place.

15.2. Those who make mental capacity assessments should be given specific guidance by Government to disclose their assessment methods and findings to carers and families of the individuals being assessed.

15.3. Whilst the Act rightly establishes an individual’s right to make bad decisions there should be guidance by Government as to when it is no longer fair and reasonable to allow them to do so persistently; and to advise how to resolve and improve such situations.

10 October 2013

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45 Mental Capacity Act 2005 Code of Practice, p.45

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Dimensions (UK) Ltd – Written evidence

1. Introduction

Dimensions (UK) Ltd is charitable Industrial and Provident Society incorporated and registered in England and Wales. Dimensions is one of the largest providers of social care, offering a range of personalised support and housing services to people with learning disabilities and autism.

We support approximately 3,000 people, employ some 5,000 staff and work with over 70 local authorities.

Our evidence of the Mental Capacity Act (MCA) 2005 is submitted based on our experience and knowledge as a provider of services.

2. Overview

In our experience, the MCA has had a mostly positive impact on the people we support. We have seen many positive outcomes as a result of the process we are required to follow.

The Act’s starting point and the presumption of capacity has helped shift the balance of power somewhat between the person being supported and the supporter; by which, in this context, we mean paid staff.

Whilst the Act has helped to clarify who the decision maker is and has also helped to distinguish between choice and duty of care, this could still be clearer. For example, a person that we support was found to be in need of dental treatment. The person was assessed as not having capacity and the family, dental practitioner and support staff debated whether or not it would be in the person’s best interests to remove the affected teeth. It was difficult to determine how much pain the person was in and if removing the teeth under a general anaesthetic would cause distress and, would this procedure improve the person’s quality of life? The family and the professionals could not agree and in this example there was confusion over who the decision maker was.

The process that the Act requires to be followed provides a definite line in the sand and has meant that we have seen practical things happen that we might not have seen before. There can be no doubt that generally there is better involvement of people in decision making. The MCA, alongside the personalisation agenda, is significantly shifting the attitudes and approaches of people in our sector.

The principles and definitions of capacity and best interests are more easily understood and are reflected in practice guidance and policy.

We believe they are appropriate and are going some way in instilling confidence in vulnerable people to speak up and challenge.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Dimensions (UK) Ltd – Written evidence

We have seen examples of this where people who are supported by Dimensions have not been satisfied with certain situations or events and they have raised this with the Board of Management. This would not have happened in years gone by.

3. Implementation

We think that the principles and guidance are clear and concise. However, one of the issues in our experience is general understanding of where the law has changed and differences in the way it should be applied.

Much of the Act is built around case law, and therefore it is not always easy to make clear judgements. Sometimes we see staff/professionals proceed to best interests without any assessment of capacity having taken place. Staff and other professionals have at times appeared wary of the assessment process - “what if I get it wrong, will I be held responsible”?

The implementation of the MCA was widely communicated to anyone who was acting in a professional capacity at that time. How well it was communicated to families, carers or individuals was, and still is, dependent on the communication channels and networks around each of these parties. Mostly this comes down to how the professionals communicate the information to each person or family unit.

Even today, whilst generally better informed and with more access to information due to technological advances, families and carers are often still reliant on personally being made aware of legislation such as the MCA by the people and agencies with whom they are in contact.

Similarly, other sectors’ knowledge and understanding of the Act is limited. It is improving but this is slow. In our experience, for example, often the banking sector is cautious, as are some departments in other institutions, such as local authority finance departments, and even, in some cases, social services departments.

Very recently we heard from a number of different people we support in various locations that they are having difficulty in accessing their money and spending it in the way they choose, and also having an uncertainty of where money comes from and who is managing it.

There are a number of external arrangements in place for people across Dimensions, including Court of Protection, named Deputies, and Appointees and Lasting Power of Attorney.

Some people we support have an Individual Budget that is agreed by their local authority and some local authorities have local schemes to safeguard people’s money.

For example, in one local authority we are aware there is a Financial Adult Safeguarding (FAS) team established to look after the finances and property of adults who:

• lack the mental capacity to manage their own financial affairs or are vulnerable to financial exploitation;
• have cashable assets less than the annually adjusted national threshold for accessing social care support from a local social services authority;

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Dimensions (UK) Ltd – Written evidence

• have no one else who is willing, able and appropriate to undertake the role of Appointee or Deputy.

Whilst this all seems very appropriate, there are clear examples where capacity has not been assumed. It is right to ask if the right decisions have been made, or if these are examples of where the process has not been followed, by-passing the assessment and jumping straight to ‘best interests’.

Alongside this we have evidence of people with learning disabilities experiencing difficulties when trying to open bank accounts. Banks often refuse to open bank accounts for people assuming that they do not have capacity. In one example, even where a parent was the Court Appointed Deputy the bank refused to open an account.

Where there is an awareness of the Act, in particular with families and carers, there can be some conflicts around “who knows best”. This is very much caught up in the power and control debate and is not always one that is easy to reconcile. Ultimately the MCA does of course assist the vulnerable person who does have capacity to make those important decisions and life choices.

We find the use of a decision making tool and agreement particularly helpful at such times. An example of a decision making agreement can be seen at www.thinkandplan.com.

The process that the Act requires to be followed provides a robust framework to ensure that enablement and protection are equally balanced, however as already mentioned, the implementation and the wariness of the process will at times result in a distorted outcome.

There has certainly been a positive step forward with the implementation of the Act and it is changing culture and practice, but progress to date has been slow. Given the high public profile of the health and social care sector, there is an opportunity to considerably further influence awareness of the Act going forward.

There is more likely to be sustainable change if the MCA remains high on political agendas.

4. Decision making

The involvement of another party to the process, such as the Court of Protection, can sometimes affect the quality of decision making by lengthening the process and influencing the outcome. The example above about access to money is a good illustration of this.

The use of Independent Mental Capacity Advocates (IMCAs) in our experience has been limited. As a provider we are not in a position to instruct the IMCAs and require the ‘responsible body’ to undertake this task, therefore access is limited. Where IMCAs have been involved the experience tends to be positive.

There is of course a cost attached to the use of an IMCA, and this could be a cause of any regional variances and the use of them.

We have seen much more involvement of families and carers in supporting people in decision making. The Act has formalised the need to involve families and carers.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Dimensions (UK) Ltd – Written evidence

5. Deprivation of Liberty Safeguards (DoLS)

The safeguards in the DoLS are adequate for care homes and hospitals. There is a general lack of certainty about what to do when someone lives in their own home or a family home.

A process for authorisation, review and challenge should be established to suit these circumstances.

6. The Court of Protection and the Office of the Public Guardian

Access to the Court of Protection and the Office of the Public Guardian are not sufficiently clear or understood. People are reliant on professionals with expertise in this area, and the professionals require a good understanding of the person they are representing. One of the issues here is that lengthy processes can mean that short to medium term planning can become very difficult, as money can take too long to come through.

The introduction of Lasting Power of Attorney (LPA) is seen as positive, however there is a concern where LPA has been granted but expectations have changed, and a person decides they want to reverse a previous decision.

7. Regulation

There has been much more focus on the areas of MCA and DoLs from the Care Quality Commission (CQC) in recent times. This, in our experience, has been adequate and appropriate.

Given that the current CQC regulations are out to consultation, with a view to changing in April 2014, the case for additional powers (if they are to be related to enforcement action) should be acknowledged and addressed during this phase.

One of the criticisms of the CQC’s current ‘essential standards for quality and safety’ is that they are not specific enough. It is hoped that the new standards, and any associated forthcoming guidance, will address this.

Other regulatory bodies who have dealings with people likely to be affected by the Act seem sometimes require more input with regards to the MCA, for example, the Health and Safety Executive.

In promoting rights and responsibilities and supporting people in decision making we have, in the past, been questioned as to whether we have acted in the best interests of a person. The limited knowledge and awareness of the Act by some other regulators has been apparent at these times.

8. Devolved administration

Our experience of the implementation of the MCA in Wales does not differ significantly.

16 August 2013

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Dr Andreas Dimopoulos (Brunel University) – Written evidence

Introduction

1. I am Lecturer in Law at Brunel University. The human rights of persons with intellectual disability are my main research interest. In Issues in Human Rights Protection of Intellectually Disabled Persons (Ashgate: 2010) I have developed a detailed argument as to how the human rights of incapacitated persons (esp. with congenital intellectual disability) should be protected under the MCA.

2. I consider that the MCA requires overhaul in relation to human rights protection, both under the HRA, as well as the CRPD. The following paragraphs briefly set out my answer to Q2 of the Call for Evidence: ‘Which areas of the Act, if any, require amendment; and how?’

3. In relation to the CRPD, it is doubtful whether the application of the capacity test in practice, which allows for substituted decision-making, conforms to Art. 12 CRPD. In relation to the HRA, considerations on the human rights protection of incapacitated persons do not form an explicit part of the best interests test.

Capacity

4. There is considerable debate in academic practice as to whether Art. 12 CRPD allows national legal systems to maintain substituted judgment making regimes. Notwithstanding this objection, the capacity test in the MCA is, in principle, not too restrictive. However, its application in practice has been problematic in several cases, because the threshold of capacity is placed too high, through expert medical opinion.

5. To take the most controversial example, courts have accepted that capacity to consent to sex requires knowledge of the mechanics of the sexual act, knowledge of the danger of sexually transmitted diseases and knowledge of the possibility of pregnancy in heterosexual intercourse [D Borough Council v AB [2011] EWHC 101 (COP)]. The consequentialist criticism I raise against such a high threshold of capacity is that it is disablist, as it excludes many persons with intellectual disability from engaging in otherwise non-coercive sexual activity, which may be of benefit to them.

6. Similarly, the approach to capacity of the courts in complex real life situations has been to fragment and compartmentalise the examination of capacity in an artificial way. To take the most recent example, in a case involving the sterilisation of a male adult with intellectual disability, it was accepted that he had the capacity to consent to sex, but lacked the capacity to decide on contraception [NHS Trust v DE [2013] EWHC 2562 (Fam)]. Given the high threshold required for capacity to consent to sex, I cannot be persuaded that a person with intellectual disability may have capacity to consent to sex but lack capacity to decide on contraception.

7. I consider that the MCA should require a holistic examination of overall capacity in complex decision-making situations. Additionally, the threshold for capacity should not be placed too high, as this runs foul of Art. 12 CRPD.

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Best interests

8. Given that the MCA does not require the examination of human rights issues in the determination of best interests, courts have generally not incorporated a rigorous human rights reasoning in their review of contested substitute-judgment making on best interests. The impression I have, reading recent cases on best interests, is that the MCA and the HRA resemble ships passing in the night: The case law on best interests has developed without any substantive reference to the human rights of the incapacitated person.

9. The welfare checklist in the determination of best interests resembles the balancing required in human rights reasoning. I consider that there is an underlying false assumption in the determination of best interests, which implies that if the decision is in the best interests of the incapacitated person, it justifies the interference with the incapacitated person’s human rights. However, decisions made in the best interests of an incapacitated person may authorise interferences, which go beyond what proportionality in human rights would allow. To take the above controversial example again, the sterilisation of an incapacitated adult male with intellectual disability in the absence of therapeutic benefit is an interference with his bodily integrity which is disproportionate to the high risk of a stressful pregnancy with his girlfriend.46

10. I consider that the determination of best interests in the MCA should proceed on the basis of the HRA. Proposed interventions in the best interests of incapacitated persons should be subject to strict control of proportionality, along human rights terms.

24 August 2013

46 http://andreasdimopoulos.wordpress.com/2013/08/17/some-contrarian-thoughts-on-re-de-2013-ewhc-2562-fam/

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Doncaster Safeguarding Adults Partnership Board – Written evidence

Overview and Context

1. To what extent has the Mental Capacity Act 2005 (MCA) achieved its aims?
   • Seen as a Social care piece of legislation.
   • Started to change, how we involve the person and their family
   • Best Interest meetings – means decisions are more focused on the person
   • Social worker practice has begun to change
   • Nothing wrong with the aims and principle are good but embedding has been poor
   • Missed the big culture shift
   • Confusion about responsibility / accountability
   • Started a culture change.
   • More focused on patient needs and not being dictated by one person.
   • Do all agencies share the same aims?
   • Risks and how they fit in duty of care.
   • Individuals in practice have conflicting dilemmas around things.
   • Whole system process not just decisions practitioners have to make

2. A) Which areas of the Act, if any, require amendment?
   B) and how?
   • Case law has since informed practice – code of practice needs updating / revising and demonstrates complex decision making
   • Lack of clarity – need to change of guidance – code of practice needs to be revised
   • Code of practice needs updating, no longer fit for purpose. Needs to include a mixture of cases that demonstrates the breath of real cases staff can become involved with. All case studies end positive – not always the case in real life.
   • MCA – Standard Forms
   • DOLS – Better forms
   • DOLS a definition of what is a DOL
   • Need a change to commissioning, use of personal budget etc
   • These issues need to be raised in order to change system

3. At the core of the MCA are its principles and definitions of capacity and best interests. Are these appropriate?
   Principles
   • Most people feel that the Principles are appropriate but it often how they are applied that is not.

Principle 1

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Doncaster Safeguarding Adults Partnership Board – Written evidence

- Assumption of capacity – in some cases, assessments conducted to evidence capacity when they only should be completed when there are doubts in this area
- People not aware of what triggers an assessment

Principle 2

- Not enough being done by staff to enabling decision making – not all steps taken to encourage P

Principle 3

- Unwise decisions – duty of care vs risk taking

Capacity

- Most people understand the definition of capacity but not all staff start at Principle 1.
- People not skilled in carrying out assessment of capacity
- Professional decision makers i.e. psychiatrists asked to assess capacity for court proceedings may have a different opinion to practitioners who work daily with P

Principle 4

Best Interests

- No definition of best interests, just use a checklist to define it. Should the best interest decision be a best interest assessment?
- Decision maker role not always clear – needs to be clarified (lack of understanding re: responsibilities / accountability)
- Sometimes BI decisions are made by staff should as a person needing to go into a care home then we let family choose which one. Can be risky letting family make choices of where the vulnerable adult should go e.g. care home.
- Best Interest” do we do what we can do within resources, or what is really in their best interests regardless of resources
- Code of practice doesn’t cover the complex and decision making and interface with other pieces of legislation
- Case law has identified that staff don’t always follow checklist and have failed to use IMCAs etc. but where they are used in BI decision making process it has been a positive.
- Case law has also emphasised the importance of taking accounts of Ps wishes and feelings, belief’s and cultures
- Best interests: decision making checklist – tends to be used for the more serious decisions but may not be used for lower level decisions
- Not sure where it fits in personal budget / interface concerns about how individuals are safeguarded
- Decisions not always followed through let families take decisions
- Not prescriptive about the different levels, not clear about

Principle 5

- Decision makers do not always look at least restrictive
- Overriding aim to protect the person

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Implementation
4. A) To what extent have the five principles of the MCA been implemented in frontline practice?

B) What evidence is available to assess this?

C) Is there a satisfactory balance between enablement and protection?

• All agencies have signed up to it locally
• Principles have been built into training
• Principles not embedded into practice in all areas
• Mainly used for more complex cases
• Used more in Social care than in health
• Local forms have been developed

• No Key Performance Indicates as it would be impossible to keep data on the day to day decisions
• Some statutory services may keep data on :

Number of Assessments of Capacity
Best Interest Decisions
Number of Advance Decisions recorded
Use of LPAs
Number of IMCAs

• But it is a difficult area to audit.
• Not a right balance between safeguarding and risk taking
• Not embedded into safeguarding procedures
• MCA add on to Safeguarding rather than at forefront of practice
• Interface between Safeguarding Adults and MCA not clear
• Local procedures not adequate
• Can be used to overpower people once someone is assessed as lacking capacity – often under control of the state.

5. A) How effective was the Government’s implementation plan?

B) What measures were taken to ensure that professionals and families of those who lack capacity know about and act in accordance with the provisions of the MCA?

C) Has it led to sustainable change?

• Started off well with a National Lead and Regional Implementation Officers
• Set up of Local Implementation had a positive outcome to enable agencies to work together but there was no monitoring of the networks
• Backed up by an appropriate budget
• No clear guidelines on how MCA monies should be used
• No standards around MCA/ DOLS
• No raising of awareness on national level

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Doncaster Safeguarding Adults Partnership Board – Written evidence

- No Statutory Forms for Assessing Capacity and recording Best Interests Decision
- Regional left to design their own
- No Statutory form for Advance Decisions
- Not built into training for social workers, nurses, doctors etc.
- Left to be dealt with locally
- No national drive
- Community engagement should be driven nationally by Government, key points: rights, LPAs and advance decisions

- Public Health need to drive it forward

6. A) Is the Act widely known and understood by professionals required to implement it?

B) How does this differ across different sectors, such as:
- health
- social care
- banking
- Other
- Embedded in some areas better than others
- More widely used by statutory agencies in health and social care
- Not widely used by other agencies such as Police, Ambulance etc.
- Different agencies have different policies and procedures – conflicting frameworks
- Lack of understanding in Independent and Voluntary sector
- Banks are more aware of LPS and Deputies
- Police have to use criminal legislation first
- MHA V MCA ambulance / Fire / Police etc. have to work within own framework
- Confusions of Duty of care / MCA

Police

Section 44 – neglect and ill treatment in criminal law, however not well used within police force.

- Social Care do not take offences to police when MCA not followed
- Enabling P to make decisions; evidence not clear how information has been communicated
- Police view that health and social staff should assess capacity – not police role
- Does P have capacity to make informed decisions re care and treatment, if no section 44 can be considered
- Positive risk taking (unwise decisions) sometimes over-rided by duty of care
- Poor capacity assessments to enable BI decisions to make person ‘safe’ – without scrutiny / reviews with decisions
- College of policing – producing guidance police officers do not assess under MCA
- Section 44, offence from a police view, is not well used nationally, hidden offence.
- Quite proactive locally,
- Leaves a lot to self-interpretation, working on a strategic
- Doesn’t fit with other legislation
- Police don’t do mental capacity assessments/ make BI decisions have own procedures.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Doncaster Safeguarding Adults Partnership Board – Written evidence

- Two types of section 44, wilful neglect and ill treatment.
- All different agencies have their own procedures.
- Different agencies conflict, they have different remits, it’s about how do we get it to work.
- Not clear who is decision maker in some cases.
- Positives: The offence itself is very positive just hidden in social care legislation.

7. A) Is the Act widely known and understood by those who are directly affected by it and by their non-professional carers?

B) To what extent does the Act provide protection and reassurance for informal carers?

C) Has the right balance between struck between protection of the carer and protection of the individual lacking capacity?

• Not clearly understood by public by the people it applies to and their carers
• Insufficient information to enable people to understand
• OPG website no longer host the public information – Ministry of Justice website harder to navigate
• Needs to be a national drive to raise public awareness
• We are making best interests decisions that aren’t really for the person but for the family, meeting carer’s needs more than the person. Some carer’s feel they know best and will sometimes do what they want. Interface between mental capacity and carer’s perception.
• Decisions made for family – not always for P – but family feel they should have input / control of decisions
• Protection for carers etc. is only when act is applied properly
• Not widely known by the general public
• Sometimes we have to meet the carers needs and not the person who we are acting in a person’s best interest
• GP etc. don’t know enough,
• Need to target training for people working with carers / families etc.
• Conflict in families acting in persons best interest
• Most informal cares are not aware of the Act.
• Sections 5 and 6 of the Act provides some protection for people carrying out tasks of care and treatment that are necessary, also protection for people spending Ps monies for necessary goods and services
• No understanding of code of practice
• National awareness public health
• Lack of interpretation by general public
• Some protection with use of LPA
• Office of the Public Guardian
• Court of Protection

8. A) Has the Act ushered in the expected?

B) or any change in the culture of care?

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
9. A) Is there any evidence that the provisions of the MCA affect some groups disproportionately?

B) If so, what data exists to compare representation across different socio-economic groups:

- Black and Minority Ethnic groups
- Gender
- No monitoring of statistics to see how ethnic minority groups come through – are health and social staff asking those questions
- Best interests to prompt challenges re P’s culture, beliefs, values etc
- BEM groups more likely to be subject to the MHA is that the same with MCA and DOLS?
  - Not all data collection includes “protective characteristics”
  - The MCA builds in protection regarding avoiding making assumptions based on a person’s age / sex / sexual preferences etc
- No data Re MCA
- Data Re DOLS on form 4 from Managing Authority but based on limited knowledge of the person from the MA

Decision making

10. A) Are those directly affected by the Act being enabled and supported to make decisions for themselves to a greater or lesser extent than they would have been in the past?

B) Does the means by which the decision is made – ‘general authority’:

- Lasting Power of Attorney
- Deputyship
- Court of protection – affect the quality of decision making?

11. What evidence is there that advance decisions to refuse treatment are being made and followed?

- Little evidence of increase in use
- Needs closer scrutiny
- Difficult to ascertain whether it is valid and applicable
- No evidence of capacity needed at time it is drawn up
- Not clear when it can be over ridden i.e. by LPA
- Information re whether someone has an AD should be collected on first contact
- Needs to be a standard Legal Form
- No register of people who have one
- Staff don’t have time and resources to find out if someone has one – what is reasonable steps?
- Not clear how it should be communicated
- P’s responsibility to ensure health are made aware of any in place
- Complex area especially in Mental Health
- No framework which assist understanding for people making it

12. Has the MCA fostered appropriate involvement of carers and families in decision-making?

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Doncaster Safeguarding Adults Partnership Board – Written evidence

• More likely to be involved in BI decision making process for more serious decisions
• Not always the case in safeguarding

13. Has the role of the Independent Mental Capacity Advocate (IMCA) succeeded in providing a voice for clients and an additional safeguard against abuse and exploitation for those who have no-one to speak to on their behalf?

• Yes the provision of the Statutory service has provide some protection
• Depends on skills of the IMCA
• Staff not clear about when they have a statutory duty to appoint an IMCA
• Safeguarding Managers do not always appoint one – need to be built into SA Procedures
• Still some confusion on when they can be used.
• Cannot get involved in mediation between families – not their role.
• The role of the IMCA is clearly defined: statutory duty to involve an IMCA in certain situations – good practice to use in safeguarding as advocate
• IMCAs have right to challenge BI decisions / take cases to court etc. – this is rarely done

Response from the IMCA Service

The IMCA service has succeeded in providing a voice for clients and although many practitioners do talk to the client, many services are risk averse and can make decisions that may not be in client’s best interests. Although official challenges are rare in the service, challenges are made regularly on behalf of the client throughout the process because of the communication between practitioners and the advocate. In the best interest meetings decisions challenges are often made and are usually resolved within that arena which is the most appropriate place. IMCA’s do safeguard the client against abuse and exploitation because it is often close family and friends that may be the ones who are taking advantage of the client’s vulnerability. IMCA’s are often involved even when there are family because they are either not acting in the best interest of the client or they are not appropriate to consult. Often when families are involved it can become all about the family member and the IMCA’s are able to cut through all that to ensure that the client is kept at the centre of the decision making process because the advocate is there for the client not for family members.

IMCAs (I think ) are adequately resourced and skilled. The initial experience required for the post is a good starting point, and on-going experience is the key to becoming a skilled worker. Additional training is sought to keep workers refreshed and build on knowledge. Regular peer/managerial supervision is extremely important in getting advice about cases etc...

Yes but where an IMCA is involved, the role is very effective at providing a voice for clients and a safeguard against abuse.

IMCAs can be very effective in providing a voice for the client. The additional requirement to ensure the MCA is being followed is very useful as it tends to mean professionals ask the IMCAs advice about the appropriate process to follow in reaching decisions. This is very different to the IMHA role, where the IMHA purely speaks for/with the client but has no power to audit the process. Working as an IMCA and as an IMHA, I feel much more professionally respected and valued in the IMCA role than in the IMHA role. That said, the In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
responsibilities the advocate takes on in the IMCA role seem to me to be much higher than the IMHA role, though the two are seen as equivalent in terms of qualifications and remuneration. The nature of the IMCA role involving life-changing decisions for the most vulnerable and isolated means the emotional load is often a heavy one.

The difficulties are

(i) The scope of the role is very narrow and there are many who do not qualify for an IMCA who would benefit. Likewise, a client may have a range of capacity related issues but the IMCA can only be involved in an accommodation decision, for instance.
(ii) Many professionals do not have a full enough understanding of the MCA and don’t necessarily make IMCA referrals when they should, or it is done very late in the process limiting the scope for IMCA involvement. There are still consultants who simply do not respond to IMCAs requests.
(iii) There is a lack of clarity and a lack of funding for related areas such as Litigation Friend. Is this part of the statutory role of the IMCA and if so, how can it be funded?
(iv) There is a lack of clarity around when IMCAs should take a case to the Court of Protection. For instance, in the situation where all professionals agree a client should go into 24 hour care, but the client wants to go home and crucially the IMCA believes that 24 hour care is in the persons best interests – what happens then? Should the IMCA take any further action (eg complaint)? Get a solicitor? Approach the OS for guidance? Make an application to Court?
(v) There is also a gap between the MCA in the Courts, with its evolving case law based on legal argument, and the MCA in practice where real world social and medical welfare decisions take effect. For instance, if someone is found to have capacity to take a specific decision, based on an assessment which takes into account the latest legal developments, does this necessarily mean they are less vulnerable? It may be that their presentation and challenges have not changed, simply their legal status. Add onto this the ending of IMCA involvement as the client has capacity, and someone may be left in a more vulnerable situation in the real world, even though legally speaking their rights have been restored.

14. A) Has the level of referrals to IMCAs met expectations?

B) What are the reasons for the regional variations in the number of referrals?

• Not the governments expectations

Reasons for variation – a lack of understanding of the MCA in some areas/by some professionals perhaps especially GPs/Care Homes around SMT decisions.

Where 39D DoLS are concerned, this is different and more fundamentally related to the DoLS and how different local authorities manage/regard deprivations of liberty.

15. Are IMCAs adequately resourced and skilled to assist in supported or substituted decision making for people lacking capacity?

• Better now than when first introduced with training for advocates being introduced.
• No on-going training

Deprivation of Liberty Safeguards

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
16. Are the safeguards in the Deprivation of Liberty Safeguards (DOLS) adequate?

- Adequate when applied properly but on whole down to the knowledge of the individual.
- No Definition of a DOL
- Code of Practice inadequate
- Forms not fit for purpose
- No guidance re forms
- Insufficient staff skilled in this area of work
- Confusion between restriction and Deprivation
- Needs to be built into safeguarding procedures
- Needs to be built into serious case reviews
- Should be the responsibility of people who are responsible for persons care.
- Not enough knowledge of DOLS by staff and Managing Authorities
- No consequences for MA when they don’t request one
- No consequences if conditions aren’t applied.
- Regulatory responsibilities are not strong enough to address issues.
- Relevant representatives maybe not fully understand their roles and responsibilities.
- Responsibility of MA to request DOLS – this is risky due to lack of understanding
- Use of restraint (misunderstanding) – no real definition of DOLS – not backed up by risk assessments use of MCA and clear procedures
- Lack of understanding between MCA/DOLS vs MHA
- Requires further guidance treated as an add on to MCA
- No regulatory responsibilities
- No BIA training developed by government – led by universities / not consistent
- Role of representative: not always understood by managing authorities
- MA don’t understand their responsibilities
- Lack of knowledge human rights act
- DOLS / not always in persons BI
- Not understood as significant harm
- Case management no oversight especially in health
- Strengthen monitoring of cases
- Training, interpretation poor
- People don’t understand powers

17. Are the processes for authorisation, review and challenge of DOLS sufficiently clear, accessible and timely?

- Paperwork time consuming.
- Under MHA got a right to appeal, under DOLS got a right to review.
- Often left to rep to challenge.
- Home / hospitals don’t realise course behind it.
- Often not enough information on forms.
- BIA’s struggle with forms. Get the training they require.
- P does not realise right to review;
- representative may not have understanding of rights
- Quality of assessments not always adequate – but process is; framework now in place to develop this
- Forms are difficult to complete; do not allow for extending text boxes etc.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Doncaster Safeguarding Adults Partnership Board – Written evidence

- Timeliness: 7 days arguable not enough for BIAs to complete assessments (7 working days)
- Number of BIAs: colleagues form health not sufficient
- MA don’t know when to trigger a report
- Internal, processes insufficient
- Getting forms from A – B
- Some very good report

The Court of Protection and the Office of the Public Guardian

18. A) Are the Court of Protection and the Office of the Public Guardian sufficiently understood and accessible to all?

B) Are they operating effectively and successfully?

There is still some confusion about the roles of the two organisations and some “mystic” about them as well as a number of myths regarding the costs of applying to the Court of Protection and the ability of the OPG to take positive action against those who financially abuse vulnerable adults.

Whilst there is a wealth of information about both the Court of Protection and the OPG on the internet not everyone has access to this or is confident enough to trawl through the different websites and pages of an organisation’s website to extract the information that they need.

With regard to the Deputyship application process many staff working in this area find it frustrating that there is little information available in easy read format when the very fact that any application to the Court of Protection is being made indicates that P’s level of understanding may be compromised. Forms such as the COP14 and annual report should at the very least be converted into easy read format so that these can be more easily shared with and, hopefully, understood by P.

Many concerns have been raised locally, regionally and nationally about the failure of the OPG to engage with local safeguarding teams and procedures.

Although OPG procedures state that local safeguarding teams will be alerted to concerns about a vulnerable adult living in that Council’s administrative area where the OPG has been asked to investigate allegations of financial abuse I and many of my colleagues can find no trace of OPG staff being the referral agent/alerter.

Other concerns have been raised regarding the time taken to process applications to the Court – experience is mixed across the country with some local authorities receiving Orders within 6-8 weeks where other councils report waiting times of 6 months plus for Orders to be granted.

For local authorities a significant issue is the payment of fees which are disproportionate with those paid to “professional” deputies – despite the fact that corporate deputies are taking on very complex cases, many which solicitors in private practice would refuse to take on.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
The current fee structure is not fit for purpose and there appears to be no mechanism for addressing this issue quickly or effectively.

19. What has been the impact of the introduction of Lasting Powers of Attorney (LPA), especially with regard to decision making on matters of personal care and welfare?

Little evidence of these – but where they do understanding of their impact on decision making can appear mixed.

Few LPA’s for Health and Welfare appear to have been “lodged” with appropriate bodies so professionals make decisions ignorant of the fact that the Attorney should be the decision maker.

Professional bodies do not have the resources to check whether there is a registered LPA for Health and Welfare in all cases – an automatic system of transferring information about LPA’s registered with the OPG (at the point of registration) to organisations such as the NHS and local authorities would ensure that the data is held centrally and accessible to those organisations’ staff working with P and ensure then that P’s wishes about who should make decisions about his health and welfare would be complied with.

20. What concerns, if any, are there regarding the costs associated with registering an LPA, or with making an application to the Court of Protection?

Evidence obtained locally indicates that the registration fee for LPA does not put people off registering the instrument, although it has been suggested that it may act as a deterrent for those wishing to financially abuse a vulnerable adult.

The fees charged by solicitors for executing LPA’s appears to vary considerably not just nationally but locally as well – this can sometimes confuse P and family members who believe that the higher fees charged means that an application is being made to the Court of Protection.

Again fees charged by solicitors for applications to the Court of Protection on behalf of lay deputies appear to vary significantly and can act as a deterrent for family members to make the application over the local authority – although councils should only make applications as a last resort.

Local authorities make significant numbers of applications to the Court of Protection and the difference in fee levels between councils and private solicitors or other third sector organisations is disproportionate, especially given the Court’s view that local authorities cannot refer cases for a Panel Deputy due to the complexity of a case or due to caseload numbers.

Increasingly local authorities are receiving requests to apply to the Court of Protection in order to obtain information relating to safeguarding investigations and where there is little evidence of assets – experience shows that solicitors are reluctant to take on cases where:

a) the value of assets are unknown
b) where assets are minimal,
c) where there is dispute amongst family members or
c) where the case is complex

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
21. A) Is legal aid available and sufficient?  
B) What impact will the recent and proposed reforms to legal aid have?  

- Only available for DOLs  
- and in some cases Human Rights issues  
- No change  

Regulation  

22. A) Is the role of the Care Quality Commission in inspecting on the MCA standards adequate and appropriate?  

B) Is there a case for additional powers? Not addressed  

23. Should other regulatory bodies, such as health and social care and professional regulators, be acting in this area? Not addressed  

Other legislation  

24. How well is the relationship with the mental health system and legislation understood in practice Not addressed  

Developed administrations and international context  

25. Does the implementation of the Mental Capacity Act differ significantly in Wales? Not addressed  

26. What lessons, if any can be learnt from the approaches taken to mental capacity legislation in Scotland and Northern Ireland, or in other jurisdictions? Not addressed  

27. A) Is the MCA compliant with the United Nations Convention on the Rights of Persons with Disability (CRPD)?  

B) Are there lessons that can be learnt from the CRPD for the successful implementation of the MCA? Not addressed  

30 August 2013
Dorset Advocacy – Written evidence

Overview and context.

1. The Act introduced new roles, bodies and powers which have provided additional statutory safeguards for people who lack capacity to make some important decisions.

2. Legal professionals may be better placed to respond to this question.

3. Yes. So many decisions are dependent on best interest information due to lack of capacity.

Implementation

4. Frontline practice rarely respects the right for a person to make an ‘unwise decision.’ Individuals are not often as involved as they could be in making decisions. IMCA reports evidence individuals’ rights and choices based on their own views and wishes as far as possible.

5. In practice it is evident that some professionals are still unclear about the Act. There are many frontline staff who have little training and opportunity to share experiences of the Act in practice. Dorset Advocacy is able to make comparisons between Local Authorities who do invest in staffing a slightly greater number of staff to support local health and social care professionals, and who are available for support on a daily basis. Where local boroughs do not invest as much there can be significant discussion about the Act and what is required from the local advocacy agency in lieu. The numbers of referrals which are inappropriately made can be equated to a lack of understanding of the Act.

6. Social care professionals appear to have a good working knowledge whilst in our experience the health sector is often unclear about the Act. This may be due to lack of training and the physicians’ perspective that they have the authority to treat as they feel appropriate. Banking and others do not tend to use the act widely therefore are unclear around capacity to sign.

7. In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Our experience suggests that the Act is little understood by non-professional and informal carers. In a smaller caring environment there would not be any measures to check the Act is providing protection and reassurance.

8. Dorset Advocacy’s experience is that more residential homes are now more aware of the Act and individuals’ rights. This is down to local training and awareness raising by advocates through their practice.

9. Geographically Dorset does not have a high rate of black and minority ethnic groups. Statistically, we are left uncertain about who makes the assessment of ethnicity. It is not clear whether referrers in the main do not state ethnicity of those referred due to an inability to ask the person directly. In recent statistics out of 114 referrals only two were from non-white backgrounds. In Dorset in general referrals are highest across Dementia cases and older people.

Decision making

10. Dorset Advocacy’s experience would suggest that those who are directly affected by the Act to be enabled and supported to make decisions for themselves is only marginally increased. The Court of Protection process is slow and there has been more emphasis on professionals getting together to make best interest decisions with varying supporting information which brings about a clear decision.

11. Dorset Advocacy has not seen any advance decisions to date.

12. Dorset Advocacy’s experience is that the MCA has fostered appropriate involvement of carers and families. However there have been occasions when professionals have disagreed with families’ wishes and tried to make decisions without consulting further.

13. The IMCA report is valued by professionals and has provided a very valuable voice for clients and case studies demonstrate successful outcomes.

Please see example case study Mr T attached.

14. The level of referrals for change of accommodation decisions have met expectations. Regional decisions in Dorset may well be the ageing population requiring decisions about staying at home with care packages or moving into residential care.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Hospitals are not referring as they should for SMT decisions. This may be ignorance of the Act or because health professionals believe they have the autonomy to make the decision.

15.

IMCA’s hold the Independent Advocacy Qualification and are therefore fully skilled and with years of advocacy experience fully able to support decision making.

The levels of referrals are often high and it is sometimes challenging to meet the increases in demand with the reduced levels of local authority funding. The need for continuing professional development is well supported locally and staff have access to the South West IMCA group of advocates and MCA leads for support. Advocates and managers regularly support the local Dorset MCA oversight group meetings and meet and converse regularly with all three MCA leads.

Deprivation of Liberty Safeguards

16.

Yes

17.

No. The DOLS paperwork has jargon that family representatives do not understand and therefore they would not challenge a DOL. IMCA involvement when appropriate and involved demonstrates a valuable voice. Locally Dorset Advocacy has seen a greater number of referrals where Advocacy support is required.

The Court of Protection and the Office of the Public Guardian

18.

Dorset Advocacy questions whether they are sufficiently understood. The helpline is a good support. There can be delays in cases being heard at the Court of Protection.

19.

Dorset Advocacy sees very few LPA cases but when involved generally most appear to be acting in the person’s best interests.

20.

The process and costs can often deter individuals in applying.

21.

It is more appropriate for other professionals to comment on this question.

Regulation

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
22.

Have not seen any evidence of the CQC inspecting the MCA standards. However Dorset Advocacy attends the local MCA oversight group meeting to which the CQC is an attendee and recent understanding shows that the MCA Leads are to expect inspection. It is questionable whether the CQC is able to fully monitor the MCA and DOLS because it has not had a role in inspecting local authorities whose decisions and practice are crucial. It can use information voluntarily submitted by local councils and information gained from inspection of care homes, hospitals and other health and social care providers, to inform its view.

23.

With health and social care decisions it may make more sense for others to act as regulatory bodies although independent bodies would be the preferred option.

Other legislation

24.

The relationship with the mental health system and legislation is not well understood in practice and sometimes there can be situations where legislation overlaps i.e. the need for an IMCA and an IMHA. Training would assist and having more partnership working, with multi trained staff, both IMHA and IMCA qualified, may offer greater understanding and improve service delivery.

Devolved administrations and international context

25.

Not in a position to comment.

26.

Not in a position to comment.

27.

Not in a position to comment.

Mr T had kyphosis (a pronounced stoop) and learning difficulties. Mr T has lived happily in a residential care home for some years. It was identified that Mr T had cataracts. His sight was deteriorating and his balance was affected. Consequently, he was becoming depressed and frustrated.

The Consultant Ophthalmologist told the IMCA advocate they were happy to proceed with surgery to remove the cataracts. After Mr T attended the anaesthetic pre assessment unit, the Consultant Anaesthetist wrote to say that he would not consider Mr T to be a candidate...
to have this repair under general anaesthetic, due to potential risks involved in managing his airway.

The residential home felt that if Mr T's cataracts could not be rectified, his care package would need to be reviewed to manage his poor vision. If Mr T's vision worsened the residential home felt that it may not be possible for him to stay with his placement and that Mr T might need to move to alternative suitable accommodation.

The IMCA spoke with health professionals and identified that there was an operating chair available which would accommodate Mr T's stoop thus reducing risks in managing his airway.

The Consultant Anaesthetist was still adamant that he would not consider Mr T for surgery.

The IMCA thought a second opinion was appropriate and spoke with a Senior Consultant Anaesthetist and the Ophthalmologist. They both agreed that the best interests pathway should be followed properly and that the benefits of Mr T receiving a cataract extraction operation would outweigh risks involved.

The Consultant Anaesthetist finally agreed to proceed with the operation.

But for the involvement of IMCA, Mr T may have lost both his sight and his home.

2 September 2013
TUESDAY 16 JULY 2013

Members present

Baroness Browning (Acting Chairman)
Lord Alderdice
Baroness Andrews
Baroness Barker
Baroness Hollins
Baroness McIntosh of Hudnall
Lord Patel of Bradford
Baroness Shephard of Northwold
Lord Swinfen
Lord Turnberg

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Witnesses

Vanda Ridley, Communications Manager, Down’s Syndrome Association, Beverley
Dawkins OBE, National Officer for Profound and Multiple Learning Disabilities, Mencap,
and Hannah Barnett, Head of Operations, National Autistic Society

Q74 The Chairman: Good morning and welcome. My name is Baroness Browning and I
am standing in for Lord Hardie, who is the Chairman of our Committee but unfortunately is
unable to be here this morning. We are very grateful to you for giving up your time to come
and give evidence to our Committee. I remind you that this is a webcast session and there
will be a transcription that will be made available to you for correction in the usual manner,
so that will follow on from today’s session. I should also, from the Chair, declare an interest
as I am a Vice-President of the National Autistic Society, which is giving evidence to us this
morning. I will try to be scrupulously fair with the information. Thank you very much.

I start with a question to all three of our witnesses today. When the Mental Capacity Act
was passed it was widely viewed as progressive and welcome legislation. From your
perspective, has the Act lived up to its expectations, and are there benefits or problems that
were not foreseen at the time that the legislation was passed? Could I begin with Vanda
Ridley, please, from the Down’s Syndrome Association?
Vanda Ridley: Yes. We think that the Mental Capacity Act has a very common-sense approach if implemented correctly. One of our concerns, I think, is around the ability of local authorities, for example, to assess correctly the capacity of people with Down’s syndrome, in that it is both time- and resource-dependent. Certainly at the moment there are limitations, because of shrinking adult care budgets, for that to be able to be done adequately.

The Chairman: Thank you very much. Beverley Dawkins from Mencap.

Beverley Dawkins: Yes, we would also agree that it was a very positive and welcome piece of legislation. I think before the Act people with a learning disability were pretty routinely excluded from many decisions that affected their lives, and decisions were plainly not always made in their best interests. We think that the Mental Capacity Act introduced a very good framework for people to have much more confidence in supporting decision-making for people with a learning disability, both with and without capacity. Again, we would echo the same concerns that implementation is probably where our biggest concern is, and probably in some specific areas such as in the definition of serious medical treatments, as set out by the confidential inquiry witnesses, where maybe some clarity is required.

The Chairman: Thank you. Hannah Barnett from the National Autistic Society.

Hannah Barnett: We were a key member of the Making Decisions Alliance decision-making body when the legislation came about, and we wanted to ensure that people had a voice; that people who struggled with communication were able to communicate their decisions better. We found in many cases that this has been the case, but again, I agree with the other two that often implementation has been quite difficult, and it does appear to be reliant on different local authorities and different people in the equation to ensure that some of the stuff is implemented appropriately.

Q75 The Chairman: Thank you very much. Could I just pick up on the point that was made by Vanda Ridley about local authorities and assessments? Is that at the point at which an assessment is being made to assess capacity or is it when there is an assessment for other decisions to be made when they fail to identify capacity in the first place?

Vanda Ridley: I think it is the assessment of capacity.

The Chairman: That should come first before any other decisions are made.

Vanda Ridley: Yes.

The Chairman: Would it be going too far to say that, in general, local authorities, which of course make a wide range of assessments about accommodation in particular—where people live and who they live with and all of that—make those decisions without thinking first, capacity?

Vanda Ridley: Definitely. Yes, I mean we have a number of cases that have come to us where decisions have been made without any recourse to the individual that it involves. We have a local authority who we have challenged on two occasions where they have not
involved the person or their family in a decision about a change of residence, and this is despite the knowledge, as far as we are aware, that they knew that there was capacity.

The Chairman: Would it be going too far to say that because of the nature that presents itself with a disability like Down’s syndrome, because it is visible if you like, that they automatically tend to defer to no capacity at all when in fact there could well be a level of capacity?

Vanda Ridley: I think so, yes, and there is also, I would say, confusion around the idea that it is each decision that should be assessed, not this blanket policy. It is sort of cultural in a sense that people still have issues with the word “assessment” and “mental”, which perhaps affects their ability to interpret the Act accordingly or appropriately.

The Chairman: Thank you very much.

Q76 Baroness Andrews: Good morning. Clearly that was about cultural change, what you have been talking about with the difficulties of implementation, but you also raised a question about the definition of serious medical treatment. I wonder whether there is scope for the Act itself to be improved in terms of any of these definitions, or indeed any of the problems of the implementation that you have identified already around the individual decision-making. Is there anything the law can do to improve implementation, shall we say? I would like to ask a supplementary about the code of practice but we can come on to that.

Beverley Dawkins: I think I made the point about serious medical treatments and it is one that the confidential inquiry witnesses and recommendations have made clear. But I am sure there could be greater clarity so that there is a much clearer definition, possibly on the face of a Bill but certainly in the code. It seems to be that that confusion results in less referral or very slow referral to IMCA, so obviously it places people in very vulnerable situations. We would certainly welcome clarity of definition. But again, when considering all of the code and the good practice and the training that has gone behind this Act, it seems to us that some practical scenarios and simple examples are required to make sure that people really understand the particular circumstances where this might apply. I think some of this is very, very practical, simple-steps information.

Baroness Andrews: If we were thinking about recommending a change in the code, would you be more concerned to see the code reflecting good current practice—because of course it was written some time ago—alongside further clarity of definitions? Is that the most useful thing you could envisage?

Vanda Ridley: Can I just raise a particular concern I think is alongside that? Following being asked to present here today, I had quite a long look at local authorities’ own guidance to practitioners and from a layman’s point of view I feel that that is adding greater complexity to the guidance of individuals who are on the ground, at the coalface or whatever, and perhaps confuses where they feel their obligations are. The Act and the code of practice are quite straightforward in terms of the steps that should be taken. Looking at some of this guidance it seems to make it much more complicated and formal. Perhaps that is just the way that local authorities operate anyway. They are large institutions; they have to have by their very nature a structure and a formality. But I think that is a problem for people who are looking after someone in a care situation.

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Baroness Andrews: Do I understand, then, that each local authority has the discretion of producing its own guidance and that is what they do? Have most local authorities produced their own guidance?

Vanda Ridley: I have just taken a sample because I just came across one and was quite surprised, so then took a sample of about eight or nine and they all had their own guidance to practitioners, and NHS authorities also have their guidance.

Q77 Baroness McIntosh of Hudnall: I am sorry, but could we just be really clear about what we are talking about here? There is a code of practice that goes with the Act that is designed to explain how to implement the Act for people whose job it is to do that, yes?

Vanda Ridley: Yes.

Baroness McIntosh of Hudnall: Are you telling us that local authorities then devise a different code of practice to do the same job that is specific to them?

Vanda Ridley: They have guidance, yes. They have guidance for practitioners in regard to the Mental Capacity Act.

Baroness McIntosh of Hudnall: What would be, in your view, the reason why they would not use the code of practice that exists and goes with the Act?

Vanda Ridley: I do not know. I honestly do not know.

The Chairman: That is very interesting and very helpful. Thank you very much indeed.

Vanda Ridley: It is incorporated within it, but they have their own guidance.

Baroness Andrews: Is it generic, or is it directed towards specific professionals? For example, is it directed at social workers or directed at health workers, or is it our version of a code, as it were?

Vanda Ridley: The ones that I have looked at are specifically guidance to practitioners, so that is from a senior social worker down to a support worker in a care home.

Lord Swinfen: I am just wondering if you are able to let us have copies of the local authorities’ codes of practices.

Vanda Ridley: I have looked at Cambridge, Walsall and Gloucestershire; those are three that come to mind. I have looked at others but, yes, I can—

Lord Swinfen: If we could have copies of them, it would be very useful, or if they are on a website somewhere, we could look at them.

Vanda Ridley: They are available on the authorities’ website.

Lord Swinfen: If you could point us in that direction, we would be grateful, because we can then have a look at them ourselves.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Vanda Ridley: Yes, certainly.

Lord Swinfen: Thank you.

Baroness Shephard of Northwold: Are the codes of practice different for different groups of practitioners, or are they the same?

Vanda Ridley: I cannot answer, sorry.

Baroness Shephard of Northwold: Of course, I would not expect you to be able to, but I just wondered if you had happened to notice. One is just looking at duplication, replication, confusion and layers of and all the rest of it. As far as you know this is our code of practice for the Mental Capacity Act, and as far as you know it goes at least to the professions you have mentioned.

Vanda Ridley: Yes.

Baroness Shephard of Northwold: Okay, thanks.

Q78 Baroness Hollins: I was just picking up on one of the recommendations of the confidential inquiry into premature mortality for people with learning disabilities, and one of the recommendations was that Mental Capacity Act training and regular updates should be mandatory for staff involved in the delivery of health or social care. The Department of Health responded by saying, “Service providers have the primary responsibility for ensuring that existing staff have the required knowledge and awareness of the Mental Capacity Act”. I suppose I am just wondering whether the guidance that you have seen was of that kind of nature, which was updates for staff locally, or whether it was a kind of alternative guidance.

Vanda Ridley: What I looked at I felt over-formalised the process of assessing capacity and set up lots of different layers that people should be looking at. I think because of that, certainly from my point of view, it created confusion, and by that token I think it would do that to people who were trying to implement it on a daily basis.

The Chairman: I am going to bring in Baroness McIntosh, but I am just floundering a bit here with a senior moment, not being able to recall a certain statute. I may be being very unfair to you, but when the Autism Act was passed and the autism strategy, as part of that, was subject to a form of statutory guidance that meant that if it was not implemented as per the autism strategy, the Minister at the centre retained the power to haul in a local authority that was not implementing that strategy. I cannot remember which section that is under, but it is pretty powerful stuff. I know I am being very unfair, but I think from what we have heard we need to check which statute applies to this guidance because clearly there are different levels of implementation. I am getting bids all around the room.

Baroness McIntosh of Hudnall: There is one other aspect of what Ms Ridley has told us that I would certainly be interested to know. When you were looking at these various guidances, did they also vary significantly one from another? Because obviously one of the issues that has come before us already is the variation in local application of the Act and, if it were the case, for example, that different local authorities are producing guidance that is
significantly different, each from the other, then that would go some way towards explaining why there were local variations. When you looked at them, were they broadly the same?

**Vanda Ridley**: I would say broadly the same, but what concerned us as an organisation was that the emphasis seemed to be upon the decision-making being very much in the role of the social worker. We did not feel that there was enough balance and support for the initial supported decision-maker.

**Baroness McIntosh of Hudnall**: Was that the case with all the guidance you looked at?

**Vanda Ridley**: Those that we looked at, yes. Obviously we did not take a complete—

**The Chairman**: Thank you. I am just going to allow Baroness Shephard to ask the final point on this. I am sure it is something we are going to want to come back to because it has been a very helpful contribution. Then we will move on because I know Baroness Barker has a question.

**Baroness Shephard of Northwold**: I just wondered whether the panel had any experience of the operation of the Mental Health Act—probably not, but if you had, whether there was a different practice with what was required with a code of conduct between the two. But if you have no experience, that is fine. It will be a question, I know, that the Committee will want to look at later on. We raised it in our very first meeting, in fact. If you do not have the experience, it is fine.

**Vanda Ridley**: No.

**Baroness Shephard of Northwold**: Thank you.

**Q79 Baroness Barker**: Thank you very much for that previous answer; it probably plays into my question. Previous witnesses have pointed up to us the difference in understanding of the Act among different professions. People have said to us that frontline social workers tend to have quite a high awareness of the Act, albeit perhaps under a form of guidance that we might not like, and in primary care, for example, it is not very good at all. Does that tie in with the experiences of the people you work with? Specifically, I would like to ask you what sort of training you think different professions would need in order to deal with issues to do with assessment and fluctuation of capacity in decision-making.

**The Chairman**: Could I ask Beverley Dawkins to kick off with an answer to this, please?

**Beverley Dawkins**: Yes. Based on our “Death by Indifference” campaign, working to address health inequalities, our perspective is very much that medical professionals are the people that we feel are most challenged by the MCA in some of the cases that we handle at Mencap. I think going before Parliament today there is an ombudsman report into the case of a young man with severe learning disabilities and a decision made by his GP in terms of epilepsy medication. I can give this to the Committee, but the ombudsman found serious service failure in regard to the Mental Capacity Act where the doctor had not seemed to consider any of the steps of the Mental Capacity Act and to make a best-interests decision in regard to the type of epilepsy medication he was prescribing, which he had changed based on cost.

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That is just a very current example, but we have many examples through our case work where certainly doctors do not seem to either follow the steps properly or in doing so are not fully involving family members in a way that they should.

**Hannah Barnett:** Perhaps I can add to that a very similar response, especially around the healthcare professionals who seem to be unwilling to carry out routine checks as people are getting older—for instance, mammograms, smear tests, those kinds of things that, at a certain age, they are going to need. They seem unwilling to do the tests or to seek a decision-making mental capacity assessment on someone to see where that sits and how we can go about achieving that, as opposed to just knocking us back at the GP door, so to speak. We do struggle with that across the UK; it is not location-specific.

Then adding to that, one of the things that we often have experienced is that a parent or family member is told that the young person they care for, or whatever it is, lacks capacity full stop. It is not based on individual decision-making, so where somebody might have capacity to make a decision around healthcare needs or where they live but not the other one. Once we have gone through it once, it seems that nobody wants to go down that route again because a decision has been made quite early on, certainly when someone is quite young, for example. We have had experiences of both.

**Q80 The Chairman:** Could I just put something to you from the Chair? People on the autistic spectrum, very often some of them will present, on a good day, as though they have full capacity on everything, but one of the things about the Act is, and we discussed this when the Act went through, was that people should be allowed to make bad decisions, like we all do. But when you have somebody, say on the autistic spectrum, for whom perhaps with a new experience they are automatically going to say no to because it is outwith their concept of what that involves, using the example you gave of somebody who might be presented as needing their first mammogram, how do you balance what the Act says about being able to say no automatically, which is what I think an awful lot of autistic people would say, and needing in their best interests to persuade them that this is needed? It is not an easy question, and I know it is not going to be an easy answer.

**Hannah Barnett:** No. Basically one of the issues that we experience with our client group is that people struggle with the consequence of events. It is the very here and now: do you want apple juice or orange juice? You can make a decision. But when it comes to the impact of the decision to have either of those, they cannot process it and see it through. So this is where we struggle. We had an example recently where somebody made it very clear they did not want to live in a certain home that they had lived in for 40 years. The family were very much, “He should stay there, as he has been there for 40 years”, and he was very clear, articulating that he did not want to do that and should he live there any longer he was going to cause quite serious harm and damage to other people. This went on to-ing and fro-ing, and, from a provider point of view, obviously the risk to us was very high that he was going to harm somebody. But what he could not say was what he wanted to do. We knew he did not want this situation, but he did not know what the alternative situations were. A lot of the work we had to do was put in the form of, “If you do not live here, this is an alternative”, but then the family were coming back in and saying, “Those alternatives should not exist because he does not know what he is saying”. That was a case where we did call in an independent advocate and it was a very successful case. It was getting quite tense between us, as you can imagine, with us speaking up on his behalf and the family speaking up...
on his behalf. It is crucial that professionals have training in autism and the understanding that you have to go back and check that decision but also give different situations and alternatives as opposed to, “Do you want to live here or here”, which might still not be enough information.

Baroness Barker: Did I understand by your answer to Baroness Andrews that you thought that there was a real need for practical simple examples? Do you have a range of examples of good practice by different professions, such as medical and social work, that could be drawn upon to be included in an updated code of practice?

Hannah Barnett: We have probably got a handful I could access.

Baroness Barker: Okay, thanks.

Q81 Lord Swinfen: Are families, carers and individuals who may lack capacity aware of and able to access their rights under the Act, including through the role of independent mental capacity advocates and the Court of Protection?

The Chairman: Who would like to start? Beverley Dawkins, can I ask you?

Beverley Dawkins: We would say no, generally families are often not aware of their rights and, as they become increasingly concerned about decisions that are being made, find it difficult to know how to challenge decisions. We have had quite a number of examples indeed where we have had to intervene in situations like that. There are many families who think that the only way that they can assist in the decision-making of an adult with a learning disability is by becoming a welfare deputy. We would suggest that if the Act was being properly followed, that would not be particularly necessary. I think families find themselves, in a variety of ways, very much on the back foot here, even when things like best-interests meetings are called and they are invited. They tell us that, “Well, everybody else had the papers days before, we did not have the papers. We got to the meeting, and it almost felt like the decision had been made”.

We had one family report to us that by the time they got to the best-interests decision meeting they got, “Four consultants think this medical decision is the right one and, no, we do not agree with you”, and not really telling them about what they could do if they strongly disagreed. I think families feel very disempowered in this process and remain quite confused about their involvement in the decision-making concerning an adult son or daughter.

Lord Swinfen: Do you do any training of the families or the person with the lack of capacity?

Beverley Dawkins: Yes, we would. We have produced a number of resources to empower families to know their rights. We have a resource—

Lord Swinfen: What do you mean by resources?

Beverley Dawkins: Fact sheets, template letters. We have a CD with lots of resources designed particularly for parents, with films to enable them to understand what their rights are. We have also developed a resource that is called “Involve me”, which is very much
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about how you can involve people, with even the most severe and profound disabilities, as much as they possibly can in decision-making. So, yes, we try to share as much information as possible. In partnership with a firm of solicitors, we produced the template letters that we give to families that say, “These are the words to use to say, ‘You need to involve me in this decision because—and these are my rights, and this is the law’’. That proves to be quite an effective—

Lord Swinfen: So far I get the impression that everything they are given is on paper. Do you sit down and discuss it with them so that they have a real chance to ask questions and to be given examples?

Beverley Dawkins: As much as we are able to. When people contact us through our helpline or we speak to them directly, yes, we are able to do that. We have had one or two very serious situations where somebody is challenging a current decision in a hospital where we have directly intervened to assist the family and advise the hospital that they are stepping out of line and what they should do in response to that situation. But these are only the circumstances we come to hear about because people have thought to call us. They may have discovered our resources on the website or asked for them through our helpline. I am sure we are not reaching anything like the number of families that it would be ideal to reach.

The Chairman: We heard evidence from officials at the Department of Health that they often refer to some of the materials produced by the charitable sector for families and carers. I wonder if I could invite all three of you to send us what you can by way of these draft letters or pamphlets or online information, because I think it would be quite good if we could start to look at what is out there and what is made available to families. I would be most grateful if you would do that; I think we would find that very helpful. I am just going to ask Lord Patel to come in, and then I am going to move on to Baroness McIntosh.

Q82 Lord Patel of Bradford: Just quickly on the whole issue of access and understanding, do you know if there are any differences for particular groups—I am particularly looking at ethnic groups—throughout the organisations in terms of families and individuals you have come across? Is there any understanding in terms of access to advocates? Is there a clear disparity or not?

Beverley Dawkins: It is hard to comment but my instinct, if you like, about that is that I am sure there are many families who probably have no understanding that the Mental Capacity Act exists, never mind thinking of contacting one of our organisations to ask for advice. I am sure there are large parts of the population, I would think, including families from ethnic minority groups, who historically do not access organisations like ourselves or services in quite the same number as other families and would be particularly vulnerable. That would just be my reaction.

Lord Patel of Bradford: Is it fair to say across the board your referral rates for minority ethnic groups would be lower than you expect?

Hannah Barnett: Again, instinctively I would say yes, but I do not have any statistics on it; certainly I have spent my career working in and around south London so it does seem there is a disparity between the amount of people that should be accessing the services and the amount of people that do access services. A lot of that is the language and the accessibility of
English being your second language, and not having the social-network environment. With more and more stuff being online and on telephones, people need to have access to that sort of equipment to be able to dip into things. Yes, I would say instinctively as well that it is, but I do not have any statistics.

_Beverley Dawkins_: Older carers perhaps as well, because there is quite an assumption that everyone has a computer and that is not the case with quite a number of the families who access us.

_The Chairman_: That is why I asked if you could send us both sets of information. Thank you.

**Q83 Baroness McIntosh of Hudnall:** This is obviously a related point, which is about the role of the IMCAs, and you have mentioned already examples of where an advocate can be a very valuable intervention. You mentioned, Ms Barnett, the person who wanted to move, and I think you said that an advocate was used in that case to resolve a problem. Broadly speaking, do you think that the introduction of IMCAs has succeeded in doing what it was intended to do, which is to give a voice to people who perhaps find it difficult to speak for themselves and have no one else? Does that therefore provide a proper safeguard or an additional safeguard against abuse or exploitation? The other issue that we have also touched on was whether the availability of IMCAs across the country is, shall we say, variable local authority by local authority. Is there a cost issue there?

_The Chairman_: Could I ask Hannah Barnett to answer, because I can see you have an answer ready?

**Hannah Barnett:** I think in our experience where we have used an IMCA they have been invaluable and absolutely fantastic. In the case I was speaking about, we had to pay for an IMCA, which does not feel right but we did, because when you need an IMCA it is like a crisis point and what we find is a lot of these situations are at crisis. It is either health, a home move, a bereavement, something like that, so it is a real instantaneous crisis and we do struggle to get an immediate response from the local authorities, from the local team. Also, in this particular case—but in a number of other cases that we have—where people are placed out of borough, the local authority do not want to give us an IMCA for that person and they say, “Go back to the local authority who is funding the placement”, who obviously do not want to send someone across the country to give us that support either.

Where we have used them, they have been absolutely fantastic. Getting them is definitely an issue, and I think also it is important to make sure that when they do turn up they have the whole picture. Again, with autism, it is important to have that understanding that it might take more than one meeting or two meetings to really get to know somebody, to understand how they are going to communicate and if they understand the consequences of any decision that they are involved in.

**Baroness McIntosh of Hudnall:** Just to go back to something that I think came up in answer to an earlier question about the serious medical condition definition, it felt to me as though there was an implication that the definition was occasionally used or not used in order to not trigger the need for an IMCA. I have put that all upside down, but I think you get what I am trying to say. Is that the case in your view?

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The Down’s Syndrome Association, Mencap and National Autistic Society – Oral evidence
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Beverley Dawkins: Yes, I think it is not identifying that it is a serious medical condition that should trigger the involvement of an IMCA. So, not enough people getting that referral would be our view. To echo what has just been said, the disparity across the country about access to IMCAs is certainly a concern. If you have the right IMCA involved in a timely fashion, who has got that whole picture, they can be an incredibly valuable contribution to that decision. But thinking particularly about people with the most profound and multiple learning disabilities who may have quite complex health needs and may be presenting in quite challenging circumstances, the time that it takes for perhaps an IMCA to understand the complexity of those issues must be very challenging for them.

Sometimes family members have commented that it has not been as helpful as they would wish because it just takes quite a lot of time to get up to speed in a challenging situation. But we have a mixed experience. Sometimes they are fantastic; other times it is very difficult getting in contact; and sometimes it is just not quite on the mark in terms of what you need to do.

Baroness McIntosh of Hudnall: Given your range of experience, all of you, would you say, first, in absolute terms, there are enough people who are able to act as IMCAs, or are we short of people to do the work? Secondly, is enough invested in training the people who are going to do that work so that they do not have to start from too low a base in considering some of the complex issues that they might have to face?

Beverley Dawkins: Again, having to answer without being conversant with all the facts, my instinct would be that there probably is still a shortage of IMCAs. In particular, given the amount of training that is needed for an IMCA involved with people who, for example, have no verbal communication and are in quite complex medical situations, I think the availability of that kind of IMCA is quite limited. It would be good to see greater investment in the training of IMCAs for people in those very complex situations, and I think people with behaviour that challenges would also be in that category so that you need to be quite a skilful person to be able to do really well in that situation.

The Chairman: The IMCAs come up frequently. I know you have all kindly come to give oral evidence to us today, but obviously we would also welcome any written submissions you may care to make and obviously your experience of IMCAs would be an ideal thing to receive in writing, if you do not mind. Thank you very much. Could I move on to Baroness Hollins, please?

Q84 Baroness Hollins: Thank you. We have heard differing views on how easy it is to assess capacity in practice, and it has been suggested that some practitioners conflate the assessment of capacity with an assessment of best interests. I wondered what your experience is of your particular client groups and people within it, the particular settings, particular professionals and how they assess capacity. How easy is it in practice, do you think?

Vanda Ridley: From our point of view, certainly most of our experience is at the very early stages with regard to the decision-making process moving on to best interests. That is where most of the calls come to us and the issues come to us. What tends to happen is that best interest is a first base. We have a number of cases, and I have gone through our records, where families are told that there is going to be a best-interests meeting when

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there does not seem to have been any assessment of capacity. There is a tendency to jump to safeguarding. Although marriage does not come under the Mental Capacity Act, as far as I understand, over the last year we have had about three cases where young people have seen a registrar or a priest, been guided and found it acceptable that they know what they are doing. Yet social care have heard about it because they have perhaps an involvement with it, and they have jumped in and called a safeguarding meeting or said that that person lacks capacity. That is, first of all, ignorance of their powers, and it is also, I think, lacking the ability to assess the situation and to assess that person’s capacity. Immediately they start ringing alarm bells.

**Baroness Hollins:** Rather a paternalistic approach.

**Vanda Ridley:** Yes, it is like, “Well, you do not know what you are doing”. Whatever the motive for it is, it is probably based on a fear of an issue of that person being at risk. However, it is not really within their remit.

**Baroness Hollins:** But in terms of assessing capacity, how easy or difficult do you think it is for your different groups, if you are going to do it properly?

**Vanda Ridley:** Yes, with Down’s syndrome in particular, there are the issues of those who are not very able, which I think Beverley has already spoken about. But young people with Down’s syndrome often have quite good language skills and so they come across as being more able than they actually are because they have learnt lots of different social cues to use. We have cases of young people who have been allowed, for example, to take out contracts and get themselves into debt because they have discussed the fact that they are able to make that decision. Parents have intervened and said, “This is not realistic, you are not understanding the abilities of this young person”, and have had to take out lasting power of attorney to be able to get control over that.

**Baroness Hollins:** Within the wider learning-disability community?

**Beverley Dawkins:** Yes, I think the people who may trouble us most would be people who have borderline capacity or perhaps even fluctuating capacity. We have come across a number of situations where the actual assumption has been that the person has capacity. They are able to make a number of decisions about large parts of their life but when it comes to perhaps a medical decision, if assessed fully, it would be shown that they perhaps could not weigh up the consequences of their decision, so they may find themselves having consented to perhaps a medical procedure without understanding the consequences.

One simple example of that recently was a young man with Down’s syndrome who was in hospital needing heart surgery. They needed him to have a number of teeth removed before the procedure could take place. The dental team had shipped up at his bedside and said, “Okay, we are going to take you down to surgery. Is it okay if we take out six of your teeth?” And he just said, “Yes, that is fine”, and his family came back to discover that he was in enormous distress. He had had no way of anticipating what that was going to be like, and indeed they had left instructions that if there were any decisions about his treatment they should be involved.

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The other thing is people assuming when people apparently refuse a procedure. A blood test is perhaps a good example of that where somebody recoils from the idea of the needle and the blood test but is not saying, “I do not want treatment for this”, or, “I do not want these tests”—they are in the here and now. We have had quite a few examples of confusion there, again from medical professionals not then thinking, “Well, perhaps we need to assess the capacity and weigh up the best interests in the circumstances”.

**Baroness Hollins:** What about with autism?

**Hannah Barnett:** As I explained earlier, I think because of the complexity of autism often the assessment of a person is done very quickly, so it could be a good day, it could be a bad day for somebody, and the language the person uses or even the colour jumper someone is wearing will have an impact on what that decision is. We believe there is real need for better understanding of autism for the people who are going to come out and do the assessments, but equally around who is triggering the fact that an assessment needs to be done, because often we find that has been us, as opposed to anybody else, and if a provider is not as conscious as we are, I would be concerned that sometimes nobody is flagging up that there needs to be an assessment or a best-interests meeting and something has just happened.

**Baroness Hollins:** It just seems as if there is a huge training and advocacy role. Beverley, you spoke earlier about the work that Mencap does, and we have heard from all of you about the work that you do to provide information, support and advocacy. Who should be doing this work, and what if, for example, Mencap or any other organisation in the third sector could not afford to do it any longer? What would happen?

**Beverley Dawkins:** Well, I think there is a huge over-reliance on a very financially stretched third sector in this regard because I think we probably all—I am sure all organisations do, too—find ourselves trying to plug some of the gaps and holes. Producing these kinds of materials and resources is an expensive and time-consuming business so, no, I think there is too much reliance perhaps on us to do that. Having said that, we are very close to the families and the client group and so we do understand very well the way these materials need to be produced. I would perhaps suggest that it is in partnership that these materials need to be produced but perhaps the third sector could be better funded in order to be able to produce these materials.

**Q85 Lord Alderdice:** You have mentioned on a couple of occasions now problems of doctors not understanding either capacity itself or the Act. I wonder if I could press you to tease it out a little bit. There are at least three groups of doctors that would come to mind: one would be general practitioners in primary care, second would be psychiatrists who might be involved, and the third would be other specialists. You mentioned particular operative procedures and so on. Do you notice any difference with these three groups in the deficits of their understanding of assessment of capacity or indeed of the Act, or is it fairly much right across the board?

**Beverley Dawkins:** I think psychiatrists would be better placed to understand these issues and may indeed take a role in helping those other doctors to understand the issues here. Our concern is probably equally spread between GP and acute hospital doctors. I think the GP level is an area that might be somewhat neglected. It is very easy to think about these
very serious decisions made by perhaps a consultant in an acute hospital but the day-to-day decisions made by a GP, for example, weighing up whether somebody should have a blood test or their blood pressure taken, are a very important step in protecting them from serious conditions developing later on.

We had a very sad case of a young man who eventually arrived in an accident and emergency department with very serious kidney failure, as was discovered, and he had never, ever had blood taken. He was quite severely autistic and everybody said, “Well, he just does not like needles”, and he would not have his blood pressure taken. If that GP had thought, “Is it in his best interests to think about how we can enable him to have it?” perhaps that might have been prevented. I think those very day-to-day things that do not seem terribly serious at the time but in the long run might prove to be so are an important part, yes.

**Lord Alderdice:** Thank you very much.

**Q86 Lord Turnberg:** You spoke earlier about carers and families feeling disempowered. From the practitioner’s point of view, do they have a reluctance to involve the carers because of their fear that they might be betraying confidences? Is there a barrier there or does the Act cover it?

**Vanda Ridley:** I think there is an element of that, certainly—they feel that they are acting in the best interests of the individual, but there seems little common sense. For example, again, for people with Down’s syndrome, and this is across the board in a way, they have difficulties with diet and weight and making healthy eating choices. As a result, we have a number of cases, again when people go into supported living when they are allowed to make a decision about eating six pies for their lunch or eating in a very unhealthy way. I am sure it would be the same for both Beverley and Hannah. Instead of looking at it in a normal practical way, which is creating an environment whereby healthy choices can be made with regard to diet, there is an element of teaching in there, of creating the right environment. It is just, “Well, that is their choice”. It is very simplistic, so they are allowed to make their own choices and their health and welfare suffer as a result. Then families feel the need to intervene and to take action.

**Beverley Dawkins:** In our experience, sometimes confidentiality has been used as a barrier to families becoming involved. So perhaps somebody is living in a residential care setting of some sort and the family are highly involved in supporting their son or daughter as much as they can; when they have wanted to question, or challenge, or just find out information about the way their son or daughter’s finances are being used, they are sometimes told, “Sorry, that is confidential”. We have advised, in a couple of circumstances, that the support and involvement of the family member was very likely to be in that person’s best interest, although you can understand some of the circumstances where maybe a small number of families may be excluded from some of that. But if you follow the steps in the Act and the code and properly consider those issues, you perhaps would come to the conclusion that it was in the best interests of that person for the family to be very involved and to be party to that information. I think some families feel that confidentiality is used as a way of shutting them out.

**The Chairman:** Is there anything you could change in the Act to improve that?
Beverley Dawkins: I do not think I can answer that here and now, but certainly we could consider that for our written—

Lord Turnberg: Do you think that the code of practice and the Act are okay? It is all a matter of balance and judgment at the end of the day, and that suggests to me that it might be the training that is needed rather than the Act. Is that a—

Hannah Barnett: I think it is about interpretation and the training when you train staff out there at the coalface, and then how they interpret that. People can use that in the two examples that were given around finances. It goes back to bad decision-making—you know, you could eat six pies maybe for the first week, you feel a bit sick, you have no money left and then you learn. But sometimes people try to jump in earlier rather than allowing people to make bad decisions. I think the training is definitely an area that could be improved for people, and then how that is interpreted and what the role of the direct support worker, the families, the actual individual, the local authority and who holds what role and how it all comes together. I would put the stress on better training.

Lord Turnberg: Right.

The Chairman: Thank you very much indeed. As a very poor Chairman I am allowing things to overrun, so if you do not mind, I am going to have to move to Lord Patel now. Thank you.

Q87 Lord Patel of Bradford: I am going to take the focus on to the deprivation of liberty safeguards. As you are aware, this came later on from the passage of the Mental Health Bill. Many have described conflicting views about it but as you may have read in some of the evidence from the Department of Health transcripts, they were quite clear that they felt the DoLS were an empowering element and that the problem, if any, existed with people focusing on the deprivation of liberty as opposed to the safeguards that were there. In your experience, do you agree with that assessment?

Vanda Ridley: I do not really have any experience of that, I am afraid.

Beverley Dawkins: I think that the deprivation of liberty safeguards are quite hard to understand, so there is poor understanding. Just to start with those words, “deprivation of liberty”, seems to set them off on the wrong foot. When you take the time to understand them and see that they are very much designed as a safeguard, you can see that they have great value—indeed, they were partly generated because of the Bournewood case and all of that, which was obviously extremely concerning. But they also get misused, and so again, families’ perception can be that they are a way of restricting sometimes their access.

Through the work we have done on the Winterbourne area, we know that people who are in assessment and treatment units sometimes have restricted access to their sons and daughters with DoLS being the reason why. So I guess this is poorly understood, especially by families. I think there was something also about the consideration of the least restrictive means of having to deprive somebody of their liberty. We have seen, certainly through the Winterbourne work, an incredible overuse of restraint and restrictive practices in the seclusion of people who may not be necessarily even detained under the Mental Health Act,
and they may not be properly within the DoLS framework either. I think there are a number of problems there.

**Hannah Barnett:** I would agree and I think one of the issues that we come across in practice is that, again, applying for deprivation of liberty is very much led by the provider of the service and not by any external agent, so the safeguarding aspect lies very much with the provider until potentially an issue has occurred. Within the legislation and again the interpretation, it is quite hazy; there is no minimum benchmark as to what is acceptable and what is not acceptable. So, again across the country within different service providers the interpretation is very much dependent on a good manager saying, “Hang on a minute, this is what we need to do and this is why we are doing it”, and then flagging up to perhaps the local authority, “Can you come in and check this and where do you think we are?”

Within our organisation we have been quite proactive in doing an assessment of needs around deprivation of liberty and around someone’s kind of lifestyle and whether we feel at any point we are doing that kind of thing. It has been a really good bit of legislation for us to check our own practice out and to look at some of the stuff we are doing. But equally, the onus is very much on the provider, I feel, and that has not been implemented by the interested parties.

**Lord Patel of Bradford:** Would you change anything, either of you, if you had an opportunity to, in respect of—

**Hannah Barnett:** The deprivation of liberty is my particular interest. The deprivation of liberty does need some clarity about what is acceptable practice but it is so difficult to do. For example, if somebody was accessing the community and going out, what would be a minimum benchmark of what people think is acceptable? It could be that somebody goes out once a week. But to do that takes a week of build-up and a huge amount of resources and staffing and transport and things like that. That is really positive as opposed to, “They have only been out once a week”, which is a really negative thing. Because of the complexity of people who would fall under this legislation, it would be really difficult to set a benchmark. But it is something that potentially should be looked at, around where that barrier is turning into unacceptable practice. I believe it sits with a manager, but nobody else is really checking out the manager’s practice. Obviously we do our own self-audits of our own services so that we have those opinions of whether what we are doing is appropriate.

**The Chairman:** Thank you very much indeed. Could I ask Baroness Shephard if she has a question to put?

**Q88 Baroness Shephard of Northwold:** Yes. All your organisations provide some form of service to people who may lack capacity—support groups right through to care homes. Do you want to add anything specifically from the perspective of being a service provider? The thing that interests me is recruitment of carer staff, for example. Are there any difficulties in finding suitable people and are there differences between urban and rural areas in supply of suitable people? In particular, in rural areas what difficulty is posed by access? When I say access, I mean people getting about.

**Vanda Ridley:** We do not provide services in the way that Mencap and AS do. However, going back to a point that was made earlier by Baroness Hollins about training, I think not...
just training but consistency of staff is the issue, because it is the relationship, the knowledge, the building-up of that knowledge that is important in making decisions about capacity.

**Hannah Barnett**: I think one of the challenges and the barriers has been, and probably will always be, the actual salary that we can offer to people at that level. Therefore, the salary we are offering determines the kind of person who is going to apply for a role. I started out 20 years ago and always wanted to do this kind of work, but the salary has probably gone up about £1,000 in 20 years.

On top of that, there has been so much legislation that has been added on top, such as what we are talking about today and deprivation of liberty, risk assessments, Health and Safety Acts and various Acts like that, that a person of entry level coming in to be a support worker does not necessarily have that skill set behind them already. English might be a second language, they might not have finished school, their literacy skills might not be that great, and now there is so much training we expect as mandatory. Obviously we should do, but it is about getting the right balance in finding somebody who wants to work for that kind of money and has the skill set to interpret a lot of this legislation and apply it appropriately. Getting that balance can be very difficult and in rural areas it can be even more difficult. But the advantage in some of our more rural environments is that we do seem to retain staff, which does give consistency. In some of the bigger cities, where we are just turning over staff the whole time, you do not get a level of consistency, but you might then get a higher calibre of staff at entry level.

**Baroness Shephard of Northwold**: That is interesting. But in rural areas, of course, the person has to be able to afford to get to the job.

**Hannah Barnett**: Yes, and then once you are there you can get out and about and there is not one bus a week that is allowing people to get into the community.

**Baroness Shephard of Northwold**: Thank you very much.

**The Chairman**: Thank you very much indeed. I think we have just one final question, which is specifically for Mencap from Baroness Hollins.

**Q89 Baroness Hollins**: Yes, quite a focused question. It is about the work you have done on death by indifference and the follow-up you have done. Do any of the cases you have been involved with meet the threshold of neglect or ill-treatment in Section 44 of the Mental Capacity Act, and, if so, are you aware of any prosecutions under that provision?

**Beverley Dawkins**: Yes. This has come up in a number of ways recently. There was consideration given following the Winterbourne events of charging people under the Mental Capacity Act, but eventually it was decided to charge them under the Mental Health Act, in fact, as it was in the recent Doncaster Solar Centre case where, again, they were charged under the Mental Health Act.

The only recent case we know of is the one referred to as the Hesley Village case where sentencing took place on 8 July, where a member of staff was found guilty under Section 44 of the Mental Capacity Act. The victim had been punched four times in the head by a care staff member. Although they were charged under the Mental Capacity Act we were

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concerned that the staff member only received a community sentence and the behaviour that challenges had been seen as a mitigating factor when the judge passed a sentence. So, we were pretty horrified by that, I would have to say. I have a paper that I would like to give to the panel, written by a lawyer who was weighing up some of the death by indifference cases—for example, the case of Martin Ryan and whether, under the Mental Capacity Act, wilful neglect might have applied. Generally he was setting out in his paper that it was incredibly hard to prove wilful neglect in those cases.

The only thing I would like to add there is that beyond criminal convictions we have been very disappointed by the failure of the GMC to take to tribunal at least three cases that we have referred to them where doctors have, in our view, failed against the Mental Capacity Act. Indeed, probably in the eyes of the ombudsman they have failed within the Mental Capacity Act. But they have not reached the point where any doctor has been given any sort of sanction, and that I find quite concerning, in that these are, in our view, unlawful actions and they do not seem to be met with appropriate sanctions.

**Baroness Hollins:** It is quite shocking. It is a lack of understanding of what challenging behaviour is and what measures a provider needs to put in place to protect both the user and the staff member, is it not?

**Beverley Dawkins:** Exactly.

**The Chairman:** Thank you very much indeed. Could I thank all three of our witnesses for attending and answering all the questions today and, of course, repeat the invitation to you to not feel this is the end of your role in our inquiry. Please feel free to contact us at any time but particularly to make any written submissions, and we look forward to receiving the literature that we discussed earlier on. Thank you all very much.
The Down’s Syndrome Association – Written evidence

The Down’s Syndrome Association (DSA) provides information and advice on all aspects of Down’s syndrome to people with Down’s syndrome (DS), their families and professionals. It is a Registered Charity established in 1970 and has a membership of over 20,000.

Over the last eighteen months the Down’s Syndrome Association has received 139 calls related to the Mental Capacity Act, in addition to email enquiries. Calls vary from blanket presumption of incapacity to unfettered decision making. The majority were from family members and about the knowledge, understanding and implementation of the Act.

• Ignorance of the Act and the support it provides.
• Concerns over a family member being subject to financial abuse
• Confusion and anxiety about the process and the legal terminology i.e. Court of Protection, Lasting Power of Attorney.
• Decisions being made on behalf of a person with Down’s syndrome without their involvement or that of the family
• Families feeling forced into taking out LPAs because of exclusion from the decision making process
• The simplistic manner in which choice is interpreted by support staff leading to concerns over health and welfare.
• Social Care misinterpreting their role in a couple’s decision to marry
• Banks and Insurance Companies – asking for Power of Attorney before issuing an account or insurance.

1. At the time it was passed the Mental Capacity Act was widely viewed as progressive and welcome legislation. Has the Act lived up to these expectations? Are there benefits or problems that were not foreseen at the time the legislation was passed?

The Mental Capacity Act, when implemented correctly, provides a common sense approach to the assessment of capacity and strikes the right balance between independence and protection. The DSA is concerned a shrinking adult care budget may be affecting the ability of local authorities to meet the requirements of the Act in regard to assessments. The cost of assessing capacity is both resource and time intensive for a person with Down’s syndrome and may be an issue for public bodies. The context, environment, mode of communication and relationship to the assessor will all impact upon the accuracy of the assessment.

2. What changes, if any, would you make to the Mental Capacity Act 2005 or Code of Practice?

3. Previous witnesses have commented on differences in understanding of the Mental Capacity Act among professional groups. Does this reflect the experiences of those that you work with? Does this change for different settings, such as hospitals, types of decision or for different types of impairment or for those with fluctuating capacity?

Families come to us because they are excluded from the decision making process or are concerned for the welfare of a relative in care/supported living. Differences in interpretation of the MCA could be due to the variety of guidance for practitioners produced by professional bodies across the country (see additional information). After sampling a number

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of these publications the DSA considers many add complexity to what should be a simple process of assessment. Large public bodies are institutions requiring structure and order to function effectively. There is a conflict between a large public body dependent on structure and an assessment of capacity which must be personalised. It is the impression of the DSA that a ‘Mental Capacity Assessment ‘is perceived as something formal by callers to the helpline, only to be carried out by professionals. Furthermore the word ‘mental’ is still considered in a negative way by many members of society, affecting both their understanding of and behaviour toward, people with Down’s syndrome and other learning disabilities.

Banking and insurance related queries are usually about their presumption of incapacity when faced with someone who has Down’s syndrome. Health queries are normally concerned with patient confidentiality.

Social Care

- Families being excluded from best interest meetings,
- Decisions regarding change of residence being made without consulting the subject of the move, or their family
- Support staff interpreting decision making in a superficial manner leading to poor diet and other health concerns. Weight is a particular issue for people with Down’s syndrome and individuals need to be supported in making positive lifestyle decisions.
- When individuals with Down’s syndrome have expressed an intention to marry, social care have instigated safeguarding proceedings or called for a mental capacity assessment.

Health

- GPs refusing to show test results to the parent of an individual unable to interpret and act upon them himself.

It is important to stress there are also examples of good practice from social workers who use best interest meetings resolve disagreements and plan a way forward without there being recourse to the COP.

4 Are families, carers and individuals who may lack capacity aware of and able to access their rights under the Act, including through the role of Independent Mental Capacity Advocates and the Court of Protection?

It is difficult to provide an accurate answer to this question, however of the calls we received regarding capacity all reflected a lack of awareness, one lady called us because she was asked by a social worker at a transition meeting if she had been to the Court of Protection yet as her son was approaching 18. It was the first time she had come across the question and was taken aback.

Transition reviews in education from age 14 provide an opportunity for families to be provided with information regarding the MCA, as the purpose of these reviews is to consider all options when planning with a young person for their future.

There is a need to demystify the Mental Capacity Act. There seems to be an over complication of something which should be straightforward. Many families we speak with for example are unaware that capacity refers to ‘each specific decision’ and is not an all or nothing matter.

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5 Has the role of the Independent Mental Capacity Advocates succeeded in providing a voice for those who have no-one to speak on their behalf, and an additional safeguard against abuse and exploitation? Do you have any concerns about the varying rates of referral across different local authorities?

We have no direct experience of this as it is usually families who approach us wanting to advocate for a family member. As an organisation we are mindful of the welfare of people with Down’s syndrome and would always refer either to an involved professional or IMCA if there were concerns.

III. Assessments of Capacity and Best interests

6 We have heard contrasting views on how easy it is to assess capacity in practice and it has been suggested that some practitioners conflate the assessment of capacity with an assessment of best interests.

(a) What is the experience of your client group of how capacity and best interests are assessed in practice? Are there issues particular to specific types of impairment, such as acquired brain injuries or dementia, particular settings or particular professionals that affect capacity assessment?

We are called when families feel excluded by social care. This is usually because a major decision such as where an individual lives has been made without their involvement, or their concerns about the welfare of their family member which have not been considered.

An assessment of the capacity of an individual with Down’s syndrome to make a decision about where they want to live is not something which can be done by asking a simple question. There must be preparatory work to explore options to ensure an understanding of the concept. The question must be asked by a familiar adult, aware of how the individual communicates, and be asked several times in a familiar environment to ensure accuracy.

A poor assessment may not give a true picture of capacity for example; individuals with Down’s syndrome with good communication skills tend to have far more problems than would be expected. Unlike people who are non verbal whose skills can be underestimated, these individuals are often believed to be more capable than they are because of their language skills. There are a number of reasons why this may happen. First, many people with DS are excellent observers with good memories. They may be able to memorise phrases, leading to the perception they understand more than they do. Second, many people want to fit into conversations and social situations and so use certain remembered phrases or comments to help them do this. Third, they may be able to converse fluently about concrete situations and concepts, leading others to assume they understand abstraction equally well.

Cases which illustrate the above:

• Support workers allowing a young man to commit to a mobile phone contract, (which was costly), because he had expressed a preference. This was despite evidence provided by parents that he lacked understanding of the consequences of his action in this case. His parents felt they had no option than to take out a Power of Attorney.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
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- Parent concerned about the deterioration of her daughter’s health prompted by marked weight gain. Her daughter is in supported living and carers say they cannot discuss the matter as it is her daughter’s choice.

(b) Do assessments of capacity and/or of best interests achieve the right balance between protection and empowerment? Are sufficient efforts made to support decision making before moving to an assessment of capacity?

Previous evidence indicates there is often insufficient support for good decision making. Individuals with Down’s syndrome need to experience decision making through frequent modelling from an early age. Too often they can be passive observers in their own lives.

There is also evidence of cases where social workers have assumed a lack of capacity and misinterpreted their responsibilities under the Act.

Relationships are an area where protection rather than empowerment is the issue.

- A mother called regarding her 22 year old daughter who was in a relationship with a man who also had DS. They intended to marry. Marriage authorities (priest/registrar) were content that both parties understood the marriage contract. The mother had received a call from a social worker out of the blue. The social worker stated that the individual did not have capacity asked all manner of what were considered to be insensitive and probing questions and be requested psychological assessment.

• Mother called regarding her daughter who was engaged to be married to a man who also had DS. The Mother wanted to discuss future planning with social services. Social services reacted by setting up a safeguarding meeting as they stated the young woman lacked capacity. A capacity assessment had not been completed but a psychiatrist was ready to carry out an IQ test. The local vicar was happy to counsel the couple before marriage.

(c) Are the law and Code of Practice sufficiently clear for practitioners and informal carers to follow? Are assessments of capacity and/or best interests happening in accordance with the Act?

Calls related to risky decision making in regard to health and money would suggest that paid carers are not supporting individuals to make their own best interests decisions. Too much reliance appears to be placed on personal choice, without an exploration of the consequences. Care staff and families need support in learning how to create opportunities to support good decision making.

7 The need for families, civil partners and carers to be consulted and involved in decisions about best interests was stressed by a number of submissions to the pre-legislative scrutiny committee. Did the final legislation and Code of Practice achieve this or are there still barriers, such as concerns around confidentiality of information or the attitudes of practitioners about involving parents of adult patients?

Calls to our helpline indicate continuing difficulties with the involvement of people with Down’s syndrome and their families in best interest decisions. The DSA has intervened twice with one particular local authority that has ignored their duties under the act. In both cases a change of residence was made without any consultation and despite knowing there was not a question of capacity.

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Mr D is in his late 20s and has Down’s syndrome. He had been placed in a different local authority from the funding authority during his education and remained there when education was completed.

He lived in a supported living situation for a few years then subsequently moved to residential care during a particularly difficult time. As Mr D was preparing to leave residential care to move back into another supported living situation, with his current providers, there were some delays and his LA were pushing hard to move him - they would be able to transfer Mr D’s financial support to the other local authority in accordance with the latest Ordinary Residence rules.

Without consulting either Mr D or his family, the funding authority contacted other providers in the new area asking them if they could provide Mr D with a placement, without consulting with Mr D or his family, and in the knowledge that he was considered to ‘have capacity’. They then proceeded to write to Mr D to inform him of their decision, resulting in a great deal of distress and hampering the progress staff at the current placement were making with him.

When it was made clear to the LA that they were required to adhere to the MCA which ‘protects his right to make his own decisions and be involved in any decisions that affect him’, they apologised and immediately involved Mr D and his family in discussions.

The LA clearly knew their responsibilities in this respect, but chose to disregard the Act in their own frustration. Neither Mr D nor his family knew their rights or how to affect the change. A formal letter spelling out the LA’s responsibilities was enough to change the course for Mr D, but the LA clearly knew what those were, and chose to disregard them.

Mr A is in his late 20’s has Down’s syndrome and lives in residential care. During his annual care review meeting, a comprehensive review of his care needs was undertaken. A positive discussion regarding his recently identified skill gaps, and the support needed to develop his independent skills, took place. Both Mr A and his mother attended the review, and although concerned about the level of need that was ascribed to Mr A (designated ‘substantial’) felt reassured that the SW had considered Mr A was well supported in his current placement. The ensuing report however, did not reflect the expected outcome of discussions that were held. In particular, the question ‘Is the home suitable for your needs?’ was answered with ‘No’. At no time during discussions was the question of the suitability of the placement addressed. All discussions took place on the premise that Mr A would continue to be offered the support that he currently gets, as well as the additional support that was identified in an additional professional report. The review report was subsequently sent to Mr A, with no further discussion. There was no consideration of his capacity to make decisions about his residence, and no attempt to discuss the content of the report with either Mr A or his mother. The LA was reminded of their duty to include Mr A in decisions affecting his care, and they consequently did.

Based on the evidence provided by the helpline, the DSA believes the majority of cases could be resolved at a local level through:

- Greater emphasis placed upon the importance of supported decision making.
- Local resolution of disagreements

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
The involvement of family/carers and associated professionals

A review of how local authorities and the NHS provide guidance to practitioners. Guidance should be consistent across the country and avoid over complexity and confusion.

Additional Information

Please find below information specifically requested by the Select Committee on the Mental Capacity Act on Tuesday 16th July 2013 during the first session of the day.

Local Authority Publications - MCA

A cursory internet search has thrown up a variety of guidance produced by Local Authorities in relation to the Mental Capacity Act; some of which is clearly for internal use and some for the general public. It is unclear in some instances whether or not the internal guidance has since been withdrawn or updated; it is of concern that it was produced at all. The guidance we have seen does not seek to replace the MCA Code of Practice; it merely seeks to interpret it for application at a local level. It is our view that some of the guidance we have seen is over complicated and, in some instances could be misleading.

Examples of Local Authority Guidance:

Walsall

cms.walsall.gov.uk/mca_revised_policy_guidance_and_forms_2_apr_10.doc (copy and paste URL into browser)

Cambridgshire

http://www.cambridgeshire.gov.uk/NR/rdonlyres/83AEA7ED-85A8-4867-844F-4B8844E5C0CC/0/MCAguidelinesredraft.pdf

Gloucestershire

http://www.gloucestershire.gov.uk/CHttpHandler.ashx?id=46026&p=0

Northants


Suffolk


Trafford


Wolverhampton

http://www2.wolverhampton.gov.uk/NR/rdonlyres/BCCC30FC-5AA0-4FE7-B5E0-58C32AFC39F0/0/practiceguidancemcamar2010.pdf

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The Down’s Syndrome Association – Written evidence

Shropshire
http://www.shropshire.gov.uk/media/296303/Mental-Capacity-Standard.pdf
Information provided by the Down’s Syndrome Association (DSA) to its members.

The DSA provides basic information about the MCA via our Helpline and in response to email enquiries. Our responses are informed by the Code of Practice. We do not provide legal advice; we signpost to third party organizations. Currently we do not produce our own resources about the MCA. However we are working with Anthony Collins, a firm of solicitors in the Midlands. They are producing some simple accessible resources and have offered to provide information sessions for our local groups.

In addition to the Code of Practice, we have found the following resources, produced by other organizations useful:

Supported Decision Making - A guide for supporters - Paradigm – 2008

HFT - Using the Mental Capacity Act - A resource for families and friends of people with learning disabilities – 2011

Thinking Ahead – A planning guide for families – FPLD – 2013

16 July 2013
The Down’s Syndrome Association – Supplementary written evidence

Further to the oral and written evidence presented to the Select Committee on the Mental Capacity Act (MCA) 16th July 2013, The Down’s Syndrome Association (DSA) would like to submit additional information based on calls it has received to its helpline since 16th July. There has been an average of two calls each week specifically relating to mental capacity. The content of the calls recorded below reflect common issues faced by our families:

- Misinterpretation of the MCA
- Incorrect information provided by local authorities and professional organisations in relation to the Act
- Exclusion of families from assessment of capacity and best interest meetings
- Care staff quality and consistency
- Lack of suitably skilled advocates.

The DSA has submitted these further case studies as it is extremely concerned about the inconsistent and sometimes incorrect interpretation of the MCA by professional bodies and local authorities.

Case Study - 1

It is clear social services acted inappropriately and against Miss X’s best interests by not providing an independent advocate to support her during the MCA assessment. The study poses the following questions:

- Does Miss X have a right to be married, particularly if she consented to it? The issue of the visa for her spouse is separate to this question. The local authority has conflated the two issues.
- Could the absence of her husband and the anxiety caused by the intervention of social services have contributed to the diagnosis of depression?
- Can Miss X be given the opportunity to have her wishes ascertained by an independent advocate? The family will abide by the court’s decisions, but want Miss X to have the opportunities all their daughters have received as British citizens.

Case Study - 2


Case Study – 3-4
These two case studies exemplify the confused and erroneous information about the MCA callers to our helpline receive from the professionals they approach for help and guidance.
Case Study – 5

The input of families is frequently disregarded by social services and valuable information about the person with Down’s syndrome is lost. In the case of Miss Z this has had tragic long term consequences.

I recently spoke with the brother of a 48 year old man with Down’s syndrome leaving home for the first time. He told me the family knew this day would come and wanted to support their brother as they felt they could make the transition to his new home a positive one. They just wanted to be involved.

The Down’s Syndrome Association recommend:

• All local authorities and professional organisation must follow the same guidance rather than produce their own based around the Code of Practice. This should include simplified version.

• Best interest disputes must have recourse to an accredited mediator. This will encourage continued collaboration between concerned parties and avoid situations being sent to the Court of Protection.

• The current confusion caused by different interpretations of the MCA across the country suggests people with Down’s syndrome and their families require not just information but access to support in regard to the assessment of capacity and best interest meetings. This is something which is not covered by the IMCA service. Families struggle to know how best to provide support and are frightened by the mention of MCA. There is no substitute for a skilled advocate able to interpret complex information for families.

• There must be a review of the training provided by local authorities and professional bodies as the evidence provided by our helpline indicates it to be inadequate. Training must be regularly updated.

Appendix 1

Case Study 1 - Failure to provide advocacy

Miss X is a 22 year old adult with Down’s syndrome. She is Bengali, but born in England. She has four older married sisters who have chosen their own partners... Miss X has witnessed these marriages and as a consequence long expressed a desire to also be married. Several years ago the family visited Bangladesh to be with a relative who had terminal cancer. He has since passed away. During this visit, Miss X began a relationship with a neighbour’s son this developed and they expressed a wish to marry. At first the parents refused but consequently they did agree and the marriage took place in 2010.

On returning to England, they applied for a spouse visa for Miss X’s husband. The application was made in 2012. The home office referred the case to social services because Miss X has Down’s syndrome. Social services called a number of meetings to discuss Miss X’s capacity to understand the consequences of marriage. They concluded that Miss X lacks a detailed understanding of the risks of pregnancy or sexual relations, and that on this basis she is mentally incapable of understanding marriage. The psychologist and district nurse also stated that Miss X might be suffering severe depression as well as signs of psychosis. The
family was shocked by the diagnosis. In the last meeting an interpretation was made that Miss X’s mother intended to take her to Bangladesh to be with her husband. This was incorrect. There was no one present at these assessments to advocate on behalf of Miss X other than her mother who’s command of English is limited. Social Services considered that Miss X was at risk and withdrew her passport. She became quite upset with this and for the first time ever, ran away. She was found by the police in an office building (a possible interpretation was that she went there to retrieve her passport). Social Services then went to the Court Protection. The family engaged a barrister (a friend of the family), who is unable to take the case further following the first hearing and will refer the case on. Miss X and her parents depend on welfare benefits and have no income.

The family is resigned to the eventual nullification of the marriage and the due process of the court.

Case Study 2 - Consistency of care and the ability to make accurate assessments.

Mrs M called as she had found no-one able to explain the decision making process in regard of her two sons one of whom is in supported living and the other who will be moving on to a residential college. Mrs M was a benefits appointee for her sons and thought this covered all decision making. She felt that many people involved in the care of her sons’ lives had no ‘investment or real interest in them’. There was a high turnover of staff in the services they accessed which meant there was no consistency of care. She felt bad decisions were being made by people who had little knowledge or understanding of the two men and their wishes. She wanted to make sure the family were included in any major decisions which needed to be made.

Case Study 3 - Administration of medication to a person with Down’s syndrome

Mrs X, who had been recently widowed, attended a meeting at her son’s school where a representative of the NHS told parents that in the context of the MCA parents were not able to administer medication to their children once they were over 18 years of age. Mrs X’s son has had problems with repeated ear infections requiring antibiotics which are prescribed by the family GP, the son requires prompting to take the medication

Case Study 4 - Signing a tenancy agreement

Parents were concerned about the manner in which their daughter’s move to supported living was becoming complicated by issues of capacity.

Miss Y has Down’s syndrome she hopes to move into supported living but the housing association are concerned she would not understand the complexities of signing a lease (many people who’s capacity is not in question have to be supported on this issue). There is evidence to show that Miss Y if properly supported is able to make decisions. While at college she was supported in making decisions about her future life. Through the use of symbols she was able to express her wish to live independently with a group of friends and have a job.

A representative of the local authority suggested that the Miss Y’s parents look into the Court of Protection. They were daunted by the prospect of finding a solicitor and meeting the costs. The parents considered the local authority were assuming a lack of capacity on

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their daughter’s behalf without there being an assessment and were concerned the local authority wanted to ‘take everything over’. The DSA provided information and guidance with regard to capacity and the understanding of tenancy. The parents then had a meeting with the housing association who stated that by having the Court of Protection it would provide greater safeguards for them as parents.

Miss Y has moved into her new home but the decision around capacity is yet to be resolved.

Case Study 5 - Involving families in decision making. A mother’s story

Miss Z is 27 years old. She went to mainstream school with support and left when 19. Following a trip to Lourdes her mother decided others could give her a better and fuller life. She began to look for supported living and prepare her for such an eventuality. Miss Z was accepted at a Mencap College. Following a successful two years, a supported living place became available and she moved in. For the first year all went well but then things changed and the management of Miss Z’s house was shared with another house. At the same time a new resident moved into Miss Z’s house, this was a person who had previously caused Miss Z anxiety because of bullying. Over the next three months the bullying resumed and coupled with a constant turnover of staff resulted in a deterioration in Miss Z’s mental health.

A new carer wrote to the support agency suggesting Miss Z was showing signs of depression, her mother disputed this stating that in her opinion Miss Z was objecting in the only way she knew how (as she has poor communication skills), to her environment. Miss Z was placed on antidepressants despite her mother’s assertion. She gained a stone in weight over two months as a result of the antidepressants. Her heart condition deteriorated and the medication was withdrawn under medical supervision. The resident causing Miss Z anxiety remained. Miss Z’s mother was asked to attend a meeting, where she met seven or eight professionals who had already been in discussion. They presented her with what she said was a ‘Mental Health Act, in a person’s best interest form’ she was asked to agree to the introduction of another antidepressant and felt pressured to give her consent. The dosage was increased one month later and within the following two weeks Miss Z took to her bed and refused to leave it or wash for thirteen weeks. During week eleven she also decided to refuse food and drink. At this point the resident causing anxiety was re housed. However for Miss Z at this point the choices were a psychiatric assessment centre or domiciliary care. The later was chosen.

After the recommended six months of stability Miss Z came off the medication. There was little improvement in that time and her former life style did not to return. The following summer, she took to her bed again and began refusing food and drink. The carers were quick to intervene, and she was placed in the assessment centre and prescribed another antidepressant to which she did not respond.

On a recent visit her mother found she had not eaten or drunk for two days, Her hands & feet were blue, her mother spoke to the doctor and an ambulance was called. Miss Z saw a consultant who diagnosed heart failure accelerated by a combination of the heat, dehydration, low blood sugar, and antidepressants. Her only treatment will be heart valve replacement in the near future.

Miss Z’s mother feels that if the knowledge and experience she had in caring for her daughter had been listened to the situation could have been averted.

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Michael du Feu – Written evidence

In response to the invitation to offer experience of using the Mental Capacity Act (MCA) 2005, I submit a summary of my opinions, gathered in my professional practice.

I am currently employed by the local authority (LSSA) as a full-time assessor both as an Approved Mental Health Professional (AMHP) under the terms of section 114 MHA, and a Best Interests Assessor, BIA for DoLS.

Part of my duties also include work as an Approved Clinician, Non medical (NHS 2008)

My day-to-day work is almost entirely with persons who suffer from organic brain changes, such as stroke, Alzheimer’s type dementia and Vascular dementia. It would be fair to point out that the work experience I have in using the MCA is with older persons in the main, post-retirement age group of mental health patients.

My work is focused on decision making for persons who may have needs they themselves do not recognise, and can put themselves, or others in harm’s way.

The main environment in which my assessments take place are those of residential care homes, including those with nursing, and hospitals.

Most of the MCA experiences I have gathered are in the Deprivation of Liberties Safeguards arena (DOLS)

I respectfully offer the following observations.

1)… As I travel around to hospitals and nursing homes, I am more often than not, dismayed by the lack of understanding held by both the care staff in front line care, and their senior staff.

I do acknowledge that I have had the benefit of significant training, to make myself eligible to act as a BIA, and perhaps those staff whose day to day work includes all manner of other duties, including the administration of a building, and the service offered, then I suppose I ought to know at least as much, if not more than the care staff and their managers in residential care home and hospital settings.

However, this legislation has been in use since 2008/9 and I am disappointed with the level of understanding I see in my daily work.

2)… There is strong reluctance for both Community Psychiatric Nurses (CPNs) and Social workers (SW) to undertake a ‘Capacity test’, and a lack of confidence about putting their own names to a decision which might be tested by the legal profession in a court of law. I have been told by a qualified and experienced SW that “…a capacity test for (residence) was not applied as I had assumed the (patient) had capacity “… This position was taken despite significant evidence that the patient was suffering from acute confusion, and had long history of Mental disorder.

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3) I am also very concerned about ‘variable capacity’ as several of the patient/residents I have seen are in this category of variable capacity. This can often be very misleading for families and staff too. The overall outcome appears to that the decisions are made on behalf of patients without recourse to an appeal. Such is the discomfort, it appears to me that once again, Guardianship would be a preferred instrument to use, if the care plan makers could include a DoL aspect to it.

There are cases where both MCA (DoLS) and Guardianship need to run side by side in order to satisfy the technical side of procedure. The danger here is that neither will be used and once again the patient will be left without an appeal mechanism. I would prefer to see an adjustment/ modification made to the existing Guardianship provision under section 7/8 MHA to allow for timely and sensible strategies to be used by the AMHP, LSSAs and Consultant Psychiatrists.

4) There is also a reluctance for some psychiatrists to involve themselves when the resident is already diagnosed, and has a stable condition, albeit the resident resents being held up in residential home. If DoLS is found to be ineligible, then guardianship can be used, but only if a non medical Approved Clinician is prepared to take on the RC role for that particular case.

5) There is also low confidence in the procedure and understanding by those same staff managers, including those in hospitals, I have the sense that for relatively minor issues, the community care staff as a whole prefer an ‘expert’ to carry out the capacity test so the author can be quoted, rather than make a decision with their own name.

6) Most of the referrals I attend for the assessment of DoLS are residents who have been at the care facility for some time. The overall assumption made by the care staff and their managers, including nurses, is that the resident being discussed, and restricted in the care plan, lacks capacity,

However, those staff and the care plans have no record of an assessment of the residents capacity being tested, and there is usually no evidence of a Best Interest Meeting, even when family visit frequently.

Some managers of care homes have requested a DoLS assessment, and then informed my office that the resident for whom they requested DoLS actually has capacity. They appeared too surprised to hear from me that the two issues are even related in some way.

7) Part of the work I am asked to do is visiting residential care homes for DoLS assessments. Some of these care homes are run a by a small family sized business. Others I visit can have several care homes all run by a large company, NB, we have no ‘Council run’ care homes in the area I work, they are all ‘private’.

As I visit each of the larger care homes that are run by a large company, I find myself saying the same things to the Nurse in charge. There appears to be no MCA ‘champion’ in these larger companies, which I think is a failing. If these larger companies had a Champion of MCA matters, I’m sure the quality of the care plans would improve quickly, and the care plans would be less restrictive to the residents as a whole.

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8) I also would comment that the MCA is less flexible in its application than the Mental health Act, and as a result staff often prefer to use the MHA in preference as it can be more relevant to older, post retirement patients. However, there is a significant issue as despite the welfare aspect of Guardianship (section 7/8 MHA) the policy makers decided to not allow DoL as part of a Guardianship care plan. This has caused many problems, as I find that there is a significant number of patients who do not qualify for DoLS (See Cheshire – west) and ‘protection of others’ and because of the limitations over DoL, they also do not qualify for guardianship.

This can lead to patients having no right of appeal against the decision made on their behalf.

It is also interesting that the case law that changes the application for DoLS entitlement can change so often, causing further confusion for front line staff.

9)…there is also an issue for older patients /resident or resistance to staff during personal care interventions, perhaps with long term resistance, or during a brief period when suffering from a urinary infection for example. I have explored this issue in some depth, and there are some who could not be prescribed sedation or anti psychotic medication because of the increased risk of stroke, for example. This can be very problematic for staff in care homes and General hospitals.

10)….Overall, in summary, I am disappointed with the DoLS aspect of the MCA in its lengthy procedures, and very long delays at the court of protection for the patient to have their appeal heard.

11)…I would offer my opinion that Guardianship under Section 7 MHA could be enhanced to include DoL and that the AMHP or LSSA could be granted more responsibility to weigh for themselves the level of restrictions required to include in a patients care plan to ensure safety. This would offer greater access to timely Appeals and be relevant for the family too.

12)….I am disappointed at the level of understanding by both front line staff and their managers and clearly a lot more training will need to be provided if those charged with caring for persons who lack capacity are ever going to be confident about when to make use of the guidance.

13)…I would also wish to see more training for community staff, perhaps with a clear format, so that they can feel better about using the capacity test for relevant decision making.

NB… I would very pleased to have an opportunity to discuss the current Guardianship limitations (section 7/8 MHA) with someone in a position of authority or influence and how modifications to the provision could reduce hospital admissions, and help to have competing strategies between MCA and MHA.

24th July 2013.
**Mr and Mrs E – Written evidence**

We attach our Evidence for consideration by the Select Committee on the Mental Capacity Act 2005.

We are the carers for HL who brought his case through the UK and European Courts which led to the introduction of the Deprivation of Liberty Safeguards. In the years since the case began we have been supporting families who have found themselves at odds with the decisions of authorities and involved with training professionals in Mental Capacity Act (MCA) and Deprivation of Liberty Safeguards (DoLs), Best Interests assessors refresher courses, advocacy organisations and informing the Department of Health during the drafting of the DoLs Code of Practice and subsequently in monitoring the progress on implementation of DoLs.

We will set out in brief points where problems with both the MCA and DoLs exist and what we believe needs to be done to address these shortcomings and illustrate these shortcomings with a few brief examples.

**Problems with Mental Capacity Act & Deprivation of Liberty Safeguards.**

1) Poor quality training and an unwillingness to engage in training. Two hour awareness training for staff of care providers is insufficient to understand and learn a new culture. Having been to training provided for providers half the audience were local authority care management who indicated they had not received MCA training. Training providers inform us that they are not often commissioned to provide these sections alongside ‘core’ units eg Hygiene, manual handling etc.

All management and supervisory staff of care providers should be able to demonstrate they have received substantial accredited training in MCA/DoLs before services are contracted to them.

All commissioners of services should be able to demonstrate the same level of knowledge.

The training needs to be nationally accredited with the lowest threshold set at the level an IMCA needs to achieve.

2) The correctness of Mental Capacity assessments needs to be strengthened, on many occasions these are not carried out by the best person to understand the decision that needs to be made, not in a setting that suits the person and with insufficient relevant information to allow the person a reasonable chance to make an informed decision. This problem is constantly faced by advocates who have the knowledge of the Act to challenge. But invariably families / informal carers know little of the Act and how it should work.

3) Best Interest decision making does not always follow the checklist. Insufficient effort is applied to understanding a person’s communication needs and how to involve them in decision making. Little time is spent on taking in the views of family, carers and other

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relevant people or considering the person’s past wishes and the least restrictive alternative.

Whilst we are going to highlight problem areas in the Deprivation of Liberty Safeguards it is our firm opinion that they must stay in place and most of the objections we have heard are based on a lack of knowledge and a lack willingness to engage with the process. Many excuses are made but it comes across that managing authorities fear that the authorization process is an interference in how they run their establishments and anyway if they stall or ignore there is little sanction on them. Supervisory bodies in many cases seem to regard the process as providing safeguards for them when depriving someone of their liberty.

4) Family members being excluded as RPR despite DoH guidance – Excuse is that because family member has a different opinion about where a person should live from the Local Authority they cannot be acting in the person’s best interest so are not fit to be RPR. If excluded as RPR there is no mechanism to challenge the exclusion. If excluded as RPR no one informs you about what is going on.

If not RPR and you wish to launch a legal challenge on behalf of your loved one you will be excluded from the legal process unless you can afford your own representation. The legal aid is taken for the person represented by the official solicitors, whose quality varies.

If you are invited to be an (unpaid) RPR then you are rarely informed you can have the services of 39D IMCA. This is a huge imbalance of power. Best Interests assessors will never be seen as independent if they work for the supervisory body and even advocates are not always seen as independent if paid for by the local authority it is unsurprising families feel powerless and resentful. However the prospective RPR should be entitled to have an IMCA’s services during the assessment process not just after appointed RPR due their almost certain lack of knowledge of the process and the MCA.

5) The spurious use of ‘safeguarding’ is another tactic employed to avoid sending people back to their own home even when family want them to. The number of home visits for toileting, changing, feeding etc is grossly inflated above how much attention a person is receiving in care, perhaps to make it a more expensive option than being in residential care. Trial visits / stays at own home to see how people manage are not contemplated. A person ‘might fall’, a person ‘might have a cooker in the kitchen’ so too dangerous. Absolutely no effort is made to think about the impact these sorts of decision have on the psychological wellbeing of the person. Ill thought out emphasis on physical safety seems paramount to Local authorities who grow more risk averse by the day. Where there are really genuine concerns as outlined in protection of vulnerable adult policies then these allegations must be investigated and proven before a family member is excluded and to aid the process perhaps Safeguarding leads should be separate from MCA/DoLs leads. Hearsay and perpetuation of rumour are unacceptable.

6) Local Authorities rarely go to the Court of Protection when people are in supported living schemes which other than a tenancy agreement are otherwise barely distinguishable from residential care where a DoL would be occurring.

7) For people who do challenge the way in which someone is being detained the process is incredibly slow. Even if the decision was successfully challenged the
Mr and Mrs E – Written evidence

damaged caused to an individual being kept in that environment while the legal course is run may be irretrievable, as was our fear in the HL case. Compare his time deprived of his liberty in 1997 (5 months) with the times it now takes to bring a case through the Court of Protection especially if you are waiting for a Local Authority to do the right thing.

8) When a Court order has been made involving place of residence and/or family contact some local authorities apparently view this as an order to alter things like contact details without returning to the court. There appears to be no scrutiny by the court that the decisions they make are being adhered to. Perhaps this is a job for Court visitors to monitor.

9) For those who cannot afford to be represented they are provided with little or no information about what is happening and what the language means. When writing to a judge to ask for such information the person was dismissed.

Examples

Case A

Young adult with learning disabilities was asked when he turned 18 by social services whether he wanted to move on or remain with his foster family. He wanted to remain and was deemed to have the capacity to make that decision. Later when the family were between residential home status and part of a shared lives programme A was removed from the home against his wishes, reasons of safeguarding concerns were cited. Placed in a ‘supported living’ placement 20 miles away from his friends, college, social networks. He repeatedly told his birth mother he wanted to go home. A was deemed not have capacity to make the decision following an assessment in a strange place without support, by an institution based psychiatrist. Local authority made responsible for action in Court of Protection after foster family brought proceedings, official solicitor acting for A meant foster family unrepresented because not eligible for legal aid. A not allowed contact with foster family, he is highly suggestible and was reported by local authority as not wanting to return to family although still telling his birth mother he did want to live with them. Local authority refused to refer for advocate and even after questions from court and their assurances they would provide one, this still had not happened several months later. Local Authority did not apply DoLs as supported living and did not voluntarily refer to Court.

Consequences are breakdown in a relationship that had sustained happily for years following a very long drawn out procedure his standard of care is reported as being far worse than he received at home, he has no contact with his friends and college and social network. No one explained how A was told or what he was told about what was happening to him and the consequences of any decisions made. No one can explained how the court order would be monitored and actions reviewed and who by.

Case B

Elderly gentleman with dementia lived in shared own home with son. Went to respite care for short break. When son saw how miserable his father was and how badly he was treated he wanted his father to return. Local Authority said he should stay in residential care. Son disagrees and managing authority ask for DoLs authorization. Son excluded as RPR without

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reason given other than he objects so can’t be acting in father’s best interests. Very expensive to mount challenges against a process you are excluded from. Son has found that independent ‘experts’ agreed by Local authority seem to provide answer LA is looking for. He has had to put up with staff accompanying him and his father on visits outside of residential home including to their own home where they have had no problem managing without staff help. Yet reports that go back to home do not always reflect that. No attempt has been made for trial home visits / stays but it is written down in one report that it is not safe at home because there is a cooker in the kitchen. This is far beyond keeping someone safe. The son is treated as a really annoying inconvenience to be dominated at all costs. There is barely any contact when Best Interests assessors review the DoL authorization. The IMCA RPR has visited the father once and that only before a court challenge. This gentleman is being appallingly served by the process and the son, like a criminal but in this case he does not seem to have a right of defence or to act in his father’s best interests.

Case C

Elderly gentleman had been living in own home with his wife. They had been living with his dementia reasonably well for five years without any social care input necessary, when a fall required his admission to hospital. Prior to return home was transferred to what was described to wife as a rehabilitation placement but which was in fact an EMI unit. Became clear to her that although she wanted him to come home there was no intention by the PCT and Social care services for that to happen. They declined any consideration of support within their home. DoL authorization process started when wife continued to object. IMCA appointed for husband and wife excluded as RPR firstly because as she objected she could not be acting in husband’s best interests and secondly, although she was not informed at the time, a safeguarding concern had been raised by one jealous step daughter. These allegations were never investigated or substantiated and neither was the opinion sought of her other step daughter who was supportive of her father returning home. The wife had to resort to raising the issues through a solicitor which then prompted action in the Court of Protection. Wife could not afford legal representation once official solicitor was involved. The official solicitor’s agent on this occasion was particularly unhelpful to the wife and none of the parties involved sought to even provide her with the most basic information about submissions to the court until the very last minute before a hearing leaving her without sufficient time to inform the court or defend herself.

Court orders made stipulated private access time to her husband in the home he had been placed – (different to that on court order). The conditions that her husband was cared for under were sufficiently bad for her to make an official complaint to social services. They did not investigate but instead reduced the private time she was allowed with her husband without returning to the court for their authorization. Social services refused her requests to move to another home and it was only after others complained about the ill treatment at the home that Social Services were forced to act and upheld what the wife had been saying all along. When an ‘independent’ investigation into Social Services actions took place the MCA/DoLs lead denied his threatening attitude or that he had refused to consider a move. In conversation with this person during this long period of time (2009-2010) it is clear his attitude was one of control and his knowledge of MCA/Dols was inadequate as he could only deal with things from an old social care perspective.

Consequences of this were that a loving couple were forced to spend the last two years of the husband’s life apart. He had demonstrated how miserable he was but social services
Mr and Mrs E – Written evidence

were not capable of interpreting this from a person centred perspective. The court process was abused by Local Authority who changed what they wanted to do threatening that they had an order that allowed them to do so. The court fails to monitor the decisions it makes. Managing authority does not act independently of supervisory body when operating in a way that deprives a person of their liberty.

Case D

Elderly man in hospital with brain tumour had discussed his future care with his son and written a letter to inform decision makers that he wanted his son to be involved with all matters. This was recorded on hospital file. Hospital decided it was time for D to be discharged but they said he could not be cared for at home. The day before this discharge the son had been very concerned about the hospital’s attitude and had challenged them about D’s mental capacity, there was no capacity assessment in file and at an emergency evening meeting with the night matron it was agreed that discharge would be delayed until the family had had a chance to look further. The following morning as the family were locating a suitable placement, news came through that their father had already been dispatched in an ambulance to a care home he had specifically stated he did not wish to go to. The discharge team said they had ‘made a verbal decision’ that D lacked capacity. No form was ever completed. They later tried to justify their decision by saying that ‘people with his condition sometimes had fluctuating capacity’. However his consultant noted on file that D had not been found to lack capacity by his doctors during his whole admission.

The consequences of the staff ignoring all principles of the Mental Capacity Act were D had capacity and was ignored. Even if he had lacked capacity his past wishes were not taken into account, his previously stated view that he wanted his son involved in all decisions was ignored. He was transported alone without knowing where he was going. His psychological as well as physical wellbeing was severely affected by being in a place he did not want to be and almost certainly hastened his death, and caused lasting friction between family members.

The Senior Nurse manager asked us to give the ward sisters an insight into the Mental Capacity Act and the impact bad decisions have on individuals and families.

Case E

Elderly woman with dementia in care home being deprived of her liberty by restricting access to her only son including being allowed to visit on Mother’s Day or being allowed to go out with her son. Originally DoLs authorization process failed because accepted that mother’s written wishes about her son being involved was sufficient for no refusals assessment. Hospital doctors said mother needed to be mobilized for periods during day but the home refused to do this. Son helped mother mobilise during his evening visits and when they went out. Home used this as a safeguarding issue and started restricting access. Leads to friction but concerns about how the home is treating residents has lead to complaints including informing police. Escalation over 3 years with no court order sought by care provider or local authority has deprived mother of access to son and social outings. Staff exercising complete control over who she sees, where and for how long. Petty safeguarding issues like ‘you were seen wheeling your mother in her wheelchair in the road’ a quiet lane which is a much smoother ride than the state of the pavements. But this is really about the breakdown of relationship with staff, taking their frustration out on mother, the refusal of

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In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Thank you for the opportunity to provide views on the Mental Capacity Act 2005. On behalf of East Sussex County Council I would like to submit the following response reflecting the views of our Deprivation of Liberty Safeguards (DOLS) Service and mental health commissioners.

In summary, the MCA is a good thing for people who have capacity, and even more of a good thing for people who may lack it. IMCAs and deputies add value to the process by providing a healthy challenge, as does the rigour of assessment and decision making. Operationally it feels to be a fair and rigorous law and truly respects people’s right to have wishes and views, and for these to be listened to when judgments are being formed about how to keep a person safe and respect their liberty.

Overview and context

1. The MCA has achieved clarity and endorsed the right for those who have capacity to make their own choices and decisions in life or to choose not to. Importantly, it gives those caring for and working with vulnerable adults a clear way to show they have considered the person’s rights and wishes/choices, and respected and upheld these. It is a vital aspect of human rights protection and the sign of a civilised society.

2. We do not see any area as needing amendment. Some workers struggle to grasp and apply the MCA, but we see this as a training and attitudinal issue, not a deficit in this empowering and liberating law.

3. The definitions of capacity and best interests are appropriate. The core principles are what make the Act an excellent tool for empowerment.

Implementation

4. Although implementation took some time to embed into frontline practice, we are confident that this is happening, not least because people with or without capacity question or challenge what is being done to them and if this truly respects their wishes, choices and liberty. Our experience is that it is rarely easy to strike a balance between enablement and protection, but this is as it should be and is a sign that things are working in the application of the MCA.

5. Implementation was robust and allowed time, although perhaps not enough, as even now workers struggle to understand how to respect other’s choices in major decision making. This is a healthy struggle though and should be ongoing. The MCA provides a clear way forward for those who need its protection to be allowed to be unsafe if they can choose to be so, and a duty on others to weigh circumstances up carefully to protect and uphold least restriction and choice if the individual cannot choose.

6. Broadly speaking the MCA is well understood by social care workers. Our experience is that Medical colleagues are able to respect a person’s right to choose in the area of medicine and treatment, but perhaps have a lesser understanding of duty of care to...
those who cannot make a decision. However, this is increasing. Solicitors are and should be well versed in the MCA principles. Nursing staff can vary; they generally have patient choice at heart, but some seem under pressure when discharge planning when a person lacks capacity. People who lack capacity and their families in contrast appear to grasp the concept of the MCA as it applies to them.

7. As stated above, those affected by the MCA and their families and friends have little trouble understanding the principles at the heart of the MCA, even when quite profoundly disabled by their condition. Most people, even with advanced dementia, Acquired Brain Injury or learning disabilities continue to have fervent wishes which others can demonstrate to them that they respect.

8. The MCA has begun to have a positive impact on the culture of care, raising awareness that loss of liberty should be a factor in managing an individual’s care and risks. One area where change has been slow is long-term residential care. In particular for people with dementia where an individual’s needs to walk and move about, and feel fresh air on their faces are at times denied. This might be more to do with staffing levels and culture and attitudes than a wish to imprison and deny basic rights. Comparatively, it is the DOLS Service’s experience that acute wards demonstrate a far greater ability to take people subject to DOLS or otherwise out and about than many long term care homes, which would seem to indicate that the problem is one of culture and attitude rather than of resources. In East Sussex the local Care Homes Dementia In Reach team has enabled an attitudinal and cultural shift in the more restrictive care homes, again indicating training and on site change management of staff practice on the ground is highly significant.

The term ‘best interest’ is now in common parlance and well understood in the same way that risk assessments became part of the established culture some years ago. Interestingly, there is a potential danger now that a culture of ‘choice’ can tip into an excuse for non-intervention and non-action and disguise neglectful care, particularly in the field of dementia care. These are skilled judgements and require training of staff at all levels.

9. The DOLS Service has seen no evidence that the provisions of the MCA affect some groups disproportionately.

Decision making

10. It is our view that in most cases those directly affected by the Act are being enabled and supported to make decisions for themselves far more than they would have been in the past. For social care workers this now involves a greater proactive management of sometimes quite unsafe arrangements in order to respect wishes and views. It has slowed down the desire to protect by moving too quickly to denying freedom. In addition, the use of the IMCAs, Power of Attorney and Deputyship and Court of Protection is now far more embedded into practice.

11. The DOLS Service has come across the use of advance decisions to refuse treatment and these have been respected, with legal advice being sought as needed.

12. Yes, as part of best interest decision making, carers and families are consulted and involved and the aim is to try to achieve consensus and agreement. Review of an authorisation and/or the complaints process supplements this process, as does greater

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confident in the last two years in using the Court of Protection when agreement cannot be reached and the person needs the protection of a court judgment.

13. Yes; through acting as a check and balance in a complex system the IMCAs are a clear success of the MCA. There is a need to ensure the availability of adequate resources to ensure the IMCA service can make a quick response in order that people have timely access to appropriately skilled advocates.

14. Referrals to the IMCA Service have met and in some cases exceeded expectations. Although difficult to pinpoint accurately reasons for variation, area psychiatric morbidity profiles and age demographics are likely to be relevant variables. It is also important that local DOLS service acts as an important influence on the ground to remind and urge the use of IMCAS in practice. It is our experience that this, and robust training on best interest decision making keeps the ESCC referral rate healthy.

15. East Sussex is part of a wider pan-Sussex Commissioning arrangement for IMCA services which enables economies of scale and transactional cost reductions to be achieved. The Service is adequately resourced and the existing provider has met and exceeded expectations in respect of service quality and adherence to contractual arrangements. ESCC review referrals and capacity rates regularly and to date the DOLS team has never been told they cannot access an IMCA.

Deprivation of Liberty Safeguards

16. The safeguards are as effective as people make them. In the past the DOLS team have sometimes struggled to get unauthorised DOLS or the unreviewed discharge of a DOLS taken up as a serious safeguarding concern, however, systematic alerting of senior managers to these events is having a positive impact. We have yet to take an unauthorised DOL or an unsafe discharge under DOLS into legal proceedings, although both have gone into safeguarding. We would like to see either considered for criminal willful neglect as other aspects of neglect under the MCA are. An additional area of interest is the role of the law (or lack thereof) in the lives of people in Supported Accommodation, where there can sometimes be situations that are very similar to the DOLS that can be authorized in care homes. It seems to be rare for professionals to involve the Court of Protection in these cases – perhaps for reasons of cost/accessibility.

17. Authorisation, review and challenge are clear in our view. It is sometimes the case that others will argue ignorance of the law as an excuse, usually when adherence to that law is a nuisance or inconvenience, not to the relevant person, but to the organisation responsible for that person. Families usually respect it and take it very seriously.

The Court of Protection and the Office of the Public Guardian

18. It is still the case that the majority of Social Workers and teams do not sufficiently understand the Court of Protection and Public Guardian. It is more widely used in Children and Families, where they can also use the fast track. For families whose relative lacks capacity and there is no Power of Attorney in place, from start to finish it can take up to 4-5 months to appoint a deputy. There is the route of using a solicitor so that they can request directions whilst waiting for the outcome of the Courts, but the costs can be high, and this can be very stressful for the relatives who are often struggling to pay care bills and in some cases to remove identifying information from the submissions.
cases trying to sell property. Most solicitors are trying to encourage people to appoint an attorney before people lose capacity, but not all take this up. There is also still a considerable amount of misunderstanding around the different powers. For example, care homes in particular have little recognition of the effects on their care giving and decision making when a family member holds LPA for Health and Welfare.

19. LPA's for finance or health and welfare do provide a safeguard, however, it must be registered by the Courts or it won't be applicable. Registration can take up to 6 weeks to complete. Once registered this gives a clear run for families to support a relative if they lose capacity, and the LPA H&W gives an extra voice for that person, to have their wishes and choices listened to. Again this can be costly, but more people are looking at both to give them more say, and in some cases have stopped a DoLS from being placed on their relative as a result. When first implemented the take up was slow to begin with, but people are more aware now and are increasingly doing this, although not so many for H&W which, again, could be down to the added cost. Most social workers have at some time contacted the Public Guardian to ensure an LPA has been registered, and have also challenged if they feel they are not working in the person’s best interest, but their own.

20. For the majority of people the costs are very high to go via the Court of Protection, and this can for the average person be off-putting. If you are computer literate, you can down load the forms and bypass solicitors and all you would pay is the Public Guardian fee. Also, if people are on benefits the fee can be waived, but from experience and listening to families, many are not applying due to the costs, some do not have access to computers, or have problems filling in the forms, or the ability to do either.

21. There is no legal aid for CoP unless people are on a very low income and the reforms are not supporting the average working person, or retired. This is unlike the support that can be given under the Mental Health Act.

Regulation

22. It is our experience that the CQC on the ground do not have a significant connection or role in either the MCA or DOLS. We are not sure that additional powers in the hands of the CQC would add anything and would perhaps only serve to add another layer of bureaucracy and institutional remedy to what are essentially individual situations.

23. We would suggest there is a need for more skilled expert experienced people deciding in MCA and DOLS. These people would have to have very particular skills, such as senior Social Workers, doctors or solicitors, to make sensible individual decisions in conjunction with a local magistrate or similar. The example of the way Guardians works in Children’s Services is helpful.

24. S12 doctors are the only professional group, alongside a small number of AMHPs also trained in DOLS, who straddle both laws. This to be more commonplace and mainstream in order to respond effectively to the needs of a growing ageing population and the associated increase in dementia.

I hope this is a constructive and helpful contribution to the work of the Select Committee and look forward to contributing further should the opportunity arise.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Peter Edwards (Director, Peter Edwards Law) – Written evidence

“What good is it making someone safer if it merely makes them miserable?” Munby J

I am a Director of Peter Edwards Law and the Head of Civil Litigation and Private Client department. I have spent my professional life representing the rights of the vulnerable and those with mental health problems. I am President of the Mental Health Lawyers Association. I provide extensive training. I am the President of mental health charity; Imagine and broadcast on radio and television.

I have held the following appointments: Consultant to Solicitors Regulation Authority, Legal Consultant to the World Health Organisation, Law Society Chief Assessor Mental Health Review Tribunal Panel, Member of Central Policy Committee of Mental Health Act Commission, Law Society Mental Health and Disability Committee, Member NACRO Advisory Committee and Member of MIND Council of Management.

My perspective is based on over 40 years experience as a solicitor spanning the divide between mental health and mental capacity in the context of representing vulnerable people. I also spend a great deal of my time training professionals and others, and through that, I am able to get a sense of how the MCA is, or is not, being implemented.

Call for Evidence. Overview and context

1. To what extent has the Mental Capacity Act 2005 (MCA) achieved its aims?

2. Which areas of the Act, if any, require amendment; and how?

3. At the core of the MCA are its principles and definitions of capacity and best interests. Are these appropriate?

4. To what extent has the Mental Capacity Act achieved its aim?

1. It is important to distinguish the Mental Capacity Act (MCA) (which, on the whole, is a well drafted and an effective piece of legislation) with deprivation of liberty safeguards (DoLS) which is, frankly, chaotic, bureaucratic and contrary to the best interests of those who are ‘detained’. Even senior judges cannot agree on what this means. (Cheshire West and Chester Council v P (2011) EWCA Civ 1257)

2. The MCA is well drafted and simple legislation which is poorly applied. This fundamentally undermines the rights of those who lack capacity and it is used as a draconic tool to control those who lack capacity for the apparent benign reason that a decision is in their ‘best interests’. The checks and balances which are in the legislation are not applied because many decision makers (D) fail to understand or apply the process of decision making contained in the MCA and its Codes of Practice. It is important to realise that judges of the Court of Protection are decision makers in exactly the same way as others and we can learn a great deal from their approach. They use the same tools. A good example of best practice can be found in the judgement of Mr Justice Hedley in the case of A Primary Care Trust v P (2009) EW Misc 10 (EWCOP).

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3. In my view, the fundamental impediments to the effective implementation of the MCA are:

A. There is a **lack of access to justice** by those who lack capacity.

4. How does the person who lacks capacity to make a particular decision at a particular time challenge, either the finding of incapacity, or the decision itself? In the case of *CC v KK and STCC* [2012] EWHC 2136 (COP), in the face of the unanimous views of both the independent expert psychiatrist and all of the professionals, Mrs KK asserted that she had capacity to make decisions concerning her residence. Mr Justice Baker agreed and stated:

   25. ‘Equally, in cases of vulnerable adults, there is a risk that all professionals involved in treating and helping that person – including, of course, a judge in the Court of Protection – may feel drawn towards an outcome that is more protective of the adult and thus, in certain circumstances, fail to carry out an assessment of capacity that is detached and objective. On the other hand, the court must be equally careful not to be influenced by sympathy for a person’s wholly understandable wish to return home.’

5. In other words, there may be a finding of lack of capacity in order to effect control of the decision making process. How very different the outcome of this case might have been if Mrs KK herself did not give evidence in the Court. It is very unusual for P to give evidence n the Court of Protection.

**How do vulnerable people access the potential protection of the MCA?**

6. It is hard to imagine an elderly person, when being told that they have got to move into a care home, reminding D of the first principle of the MCA. The old adage that ‘knowledge is power’ is very true and when you are dealing with very vulnerable people, it is very difficult for them to access that information.

7. There is an interesting contrast with the Mental Health Act (MHA) when a person is detained under section. There is a statutory obligation on the managers (Section 132) that requires them to take steps to ensure that a person ‘understands’ their rights. I appreciate that this relates to those who are ‘detained’. However, who has the obligation to ensure that those who lack capacity understand what rights they have under the MCA? No one.

**So how can a person who lacks capacity instruct a solicitor?**

8. The relationship between a solicitor and client is contractually based and if the client lacks capacity to enter into such a contract, strictly speaking they are left without the ability to seek legal advice. I have been seeking clarification from both the Law Society and Solicitors Regulation Authority on this for many years without success. The Official Solicitor will only get involved in a case involving incapacitated adults if invited by the Court. But how does the case get to court for them to be invited? Also, there are many cases where what is required is advice, not litigation.

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B. There is a misconception that only doctor’s can assess capacity (when in fact many doctors have never any training on how to assess capacity).

C. There is a misconception that capacity assessments and best interest decisions bind staff (when of course the role of D is time and decision specific).

D. There is a misconception that the ‘next of kin’ posses decision making powers. This is constantly reinforced by health and social services who ask people who their next of kin is.

E. Professionals seem to spend a lot of time at ‘best interests’ meetings. There is often little or no evidence that before best interest decisions are made, that the relevant person (P) has been assessed as lacking capacity. The first principle of the MCA is that all adults have capacity unless there is evidence they don’t. The term ‘best interests’ has become a holy grail and when a decision is made by the best interests meeting that seems to bind subsequent action by professionals.

F. The most fundamental problem of all is linked to point 4 above. Health and social services professionals tend to make decisions by committee, whereas the MCA is about the individual responsibility of D.

G. Problems are exacerbated by attempts by organisations to codify the MCA into operational procedures. This can have a stultifying effect. It can undermine the very principle that the buck stops with D and decision making is time and decision specific.

H. Because the word ‘mental’ is included in the title there is an assumption that you do not need to incorporate the basic principles of the MCA into practice unless you work in the world of ‘mental’. This was well illustrated in the case of Commissioner of Police for the Metropolis v Z [2013] EWCA Civ 69. This was an appeal by the Metropolitan Police in relation to the action of the police officers in controlling a young autistic boy at a swimming pool. The police had sought to argue (inter alia) that the MCA was overridden by operational necessity. The Court of Appeal robustly rejected this. Lord Dyson (para 49):

“the MCA does not impose impossible demands on those who do acts in connection with the care or treatment of others. It requires no more than what is reasonable, practicable and appropriate. What that entails depends on all the circumstances of the case.”

‘It was therefore open to the judge to hold, as he did, that the officers had not acted in ZH’s best interests’. (para 50).

9. The growth of the ‘safeguarding industry’ and how safeguarding relates to the Mental Capacity Act is a complex issue and troubles me greatly. Safeguarding vulnerable adults is vital. But this has become an industry in itself and can be used not to safeguard but to control. The vulnerable person, in being ‘protected’ might be removed from their own home environment. They may well feel as though it is they who are being punished. In the case of Re MM (an adult) [2007] EWHC 2003 (Fam) Mr Justice Munby (as he then was) stated:

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118. The fact is that in this type of case the court is exercising an essentially protective jurisdiction. The court should intervene only where there is a need to protect a vulnerable adult from abuse or the real possibility of abuse…. The jurisdiction is to be invoked if, but only if, there is a demonstrated need to protect a vulnerable adult. And the court must be careful to ensure that in rescuing a vulnerable adult from one type of abuse it does not expose her to the risk of treatment at the hands of the State which, however well intentioned, can itself end up being abusive of her dignity, her happiness and indeed of her human rights. That said, the law must always be astute to protect the weak and helpless, not least in circumstances where, as often happens in such cases, the very people they need to be protected from are their own relatives, partners or friends.’

120. A great judge once said, "all life is an experiment," adding that "every year if not every day we have to wager our salvation upon some prophecy based upon imperfect knowledge" (see Holmes J in Abrams v United States (1919) 250 US 616 at pages 624, 630). The fact is that all life involves risk, and the young, the elderly and the vulnerable, are exposed to additional risks and to risks they are less well equipped than others to cope with. But just as wise parents resist the temptation to keep their children metaphorically wrapped up in cotton wool, so too we must avoid the temptation always to put the physical health and safety of the elderly and the vulnerable before everything else. Often it will be appropriate to do so, but not always. Physical health and safety can sometimes be bought at too high a price in happiness and emotional welfare. The emphasis must be on sensible risk appraisal, not striving to avoid all risk, whatever the price, but instead seeking a proper balance and being willing to tolerate manageable or acceptable risks as the price appropriately to be paid in order to achieve some other good – in particular to achieve the vital good of the elderly or vulnerable person’s happiness. What good is it making someone safer if it merely makes them miserable?

10. Little is often said about the large sums of money lost by incapacitated people in legal costs in the Court of Protection. These cases may cost many thousands of pounds. P may not be eligible for legal aid and even if they are they are likely to lose any funds they have in excess of £3000 by way of legal aid contributions.

11. One of the fundamental problems with the implementation of the MCA is that health and social services like to make, what I call, 'group decisions'. People get around tables and discuss and debate (often without an understanding of the legal framework or access to legal advice) and then make decisions. This is completely at odds with the principles of the MCA in that capacity is time and decision specific. People can get labelled 'incapacitated' as though this is an ongoing and permanent state that relates to all decisions.

12. The labelling of somebody as incapacitated removes all of their rights and powers of decision making.

13. There is a false notion that the MCA is 'less restrictive' that the Mental Health Act. How can that be when the MCA can be used to effect total control without deprivation of liberty? It is worth recalling the words of Lord Steyn when he eloquently expressed concern about the powers of the common law doctrine of necessity in the House of Lords decision in R v Bournewood Community and Mental Health NHS Trust Ex p. L [1999] 1 AC 458:

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'The common law principle of necessity is a useful concept, but it contains none of the safeguards of the Act of 1983. It places effective and unqualified control in the hands of the hospital psychiatrist and other health care professionals. It is, of course, true that such professionals owe a duty of care to patients and that they will almost invariably act in what they consider to be the best interests of the patient. But neither habeas corpus nor judicial review are sufficient safeguards against misjudgments and professional lapses in the case of compliant incapacitated patients. Given that such patients are diagnostically indistinguishable from compulsory incapacitated patients, there is no reason to withhold the specific and effective protections of the Act of 1983 from a large class of vulnerable mentally incapacitated individuals. Their moral right to be treated with dignity requires nothing less. The only comfort is that counsel for the Secretary of State has assured the House that reform of the law is under active consideration.'

14. In my experience many professionals (especially health professionals) are still making decisions in the same way that they did under the common law doctrine of necessity.

Implementation

4. To what extent have the five principles of the MCA been implemented in frontline practice? What evidence is available to assess this? Is there a satisfactory balance between enablement and protection?

15. It is my view that as far as the legislation is concerned, there is a satisfactory balance. However, the fundamental problem is that in order to properly implement the provisions of the MCA this requires a change of culture. From my experience, whilst the five principles are excellent, there is a fundamental problem in that people rarely seem to understand who the decision maker is or the fundamental importance of their role. Clearly it is D’s responsibility to implement the principles. If this does not happen then what chance of the decision making process working effectively?

16. The importance of statutory codes was set out in the decision of R (Munjaz) v Ashworth Hospital Authority (2005) UKHL 58. This was then incorporated into the introduction to the Code of Practice to the MHA (as amended in 2007).

‘While the Act does not impose a legal duty to comply with the Code, the people listed above to whom the Code is addressed must have regard to the Code. The reasons for any departure should be recorded. Departures from the Code could give rise to legal challenge, and a court, in reviewing any departure from the Code, will scrutinise the reasons for the departure to ensure that there is sufficiently convincing justification in the circumstances.’

17. This would apply equally to the MCA and DoLS Codes. In other words when making decisions the starting point would be the Code. It either has to be followed or reasons for departure recorded. In my experience most professionals have not read any of the Codes. If they had, I suspect we would not have the problems that now exist.

18. The principles of the MCA are very good but from my experience, the second principle is rarely acknowledged and myself and my staff have spend over the years many hours reading thousands of pages of notes during the course of our work and it is rare that one finds documentary evidence that the second principle has been even consider or acknowledged.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
19. Another common problem is that there seems to be an assumption of incapacity rather than an assumption of capacity. There seems to be a discriminatory practice that when dealing with certain client groups e.g. the elderly or learning disabled, it is for them to show that they have capacity. Old habits die hard.

20. In my experience, with certain professional groups, (especially nurses and doctors), when asking them to justify decision making, they adhere very closely to the concept of ‘best interests’. ‘It is in their best interests’ is seen as a justification for taking control. When we ask for evidence of a capacity assessment that is the step they have often missed. In other words, the first three principles are ignored.

5. How effective was the Government's implementation plan? What measures were taken to ensure that professionals and families of those who lack capacity know about and act in accordance with the provisions of the MCA? Has it led to sustainable change?

21. There is no doubt the Government invested large sums of money in training to try and ensure the MCA was properly adhered to. It was supported by an excellent Code of Practice. I believe the implementation plan failed in part because most professionals and other decision makers have never read the Code of Practice. I would suggest that many do not even know of its existence. It is certainly not used as the tool for effective and lawful decision making for which it was in part designed.

22. I fear that many trainers still take a routinised approach to teaching. Unless a cultural and ethical approach accompanies the legal training, my view is that it is impossible for frontline staff or any other decision makers, to link the MCA with their day to day decision making. It has to be integrated into the way people work and the way people approach their contact with vulnerable people. It is not apparent to me what, if any, training doctors or other health care professionals get in how to incorporate the MCA in to their day to day working practices.

23. I believe that there is a divide between those who write policies and procedures and those who provide the frontline service. It is noteworthy that my training sessions are often attended by frontline staff (with the notable exception of doctors, managers and policy makers are not there. Those who attend may hear a trainer correctly set out the law but there may be a disconnect between this and their experiences at work.

24. Surely the purpose of training is to ensure a consistent application of the law into practice. Whether your rights are respected should not depend on who is on duty. In an ideal world the policies and procedures would be the tool by which this is audited and delivered. In my experience there is a total disconnect between policies and procedures, training and the actions of frontline staff. This fundamentally undermines the effectiveness of the MCA and its ability to protect the rights of vulnerable people.

6. Is the Act widely known and understood by professionals required to implement it? How does this differ across different sectors, such as health, social care, banking and others?
25. I do think that the MCA has been a force for good and I think there is a slow attitudinal change taking place. It is just a shame that much of that change seems to be driven by litigation.

26. As a human rights lawyer, I have a passionate belief that people should be encouraged to respect the law and implement it rather than wait to challenge people when they don’t implement it properly. The Court of Protection is littered with cases where, especially local authorities have failed to take appropriate steps.

27. In the case of G v E, Manchester City Council and F (costs) [2010] EWHC 3385 (Fam) the Court of Protection took the unusual step of awarding costs against Manchester City Council. Although never officially revealed it is believed that this may have cost the citizens of Manchester somewhere approaching £1 million. Mr Justice Baker stated:

41. In this case, however, I am entirely satisfied that the local authority’s blatant disregard of the processes of the MCA and their obligation to respect E’s rights under the ECHR amount to misconduct which justifies departing from the general rule. Miss Irving boldly relies on the ignorance of the local authority’s staff as an excuse and submits that the complexity of the statutory provisions left large numbers of professionals uncertain as to the meaning of “deprivation of liberty”. Given the enormous responsibilities put upon local authorities under the MCA, it was surely incumbent on the management team to ensure that their staff were fully trained and properly informed about the new provisions. If a local authority is uncertain whether its proposed actions amount to a deprivation of liberty, it must apply to the Court. As it is, the local authority’s actions in this case would have infringed E’s Article 5 and 8 rights under the old law as well as under the MCA.

28. The answer is emphatically no. I have been training in this field for over 35 years and my view is that there must be a fundamental flaw with basic training, particularly of doctors and nurses, because they don’t seem to have the necessary mindset to implement the legislation.

29. If Parliament did make an error with the MCA, it was to add the word ‘Mental’ in front of the words ‘Capacity Act’. This has created a myth that unless you work in the world of ‘mental’, the MCA is nothing to do with you. I think it is fundamentally wrong to believe that the problem in correctly implementing the MCA can be improved by a change in the legislation. That simply is wrong. It is a cultural change that is required to allow a good piece of legislation to be implemented properly. You ask whether the understanding differs across various sectors and my belief is that it doesn’t. There are clearly some professionals who have an excellent understanding of the MCA and implement the Codes of Practice into their day to day practices. However, I find these people the exception rather than the rule. Where you do find them, they tend to come from the ranks of social services.
30. You ask whether the right balance has been struck between the protection of the carer and the protection of the individual lacking capacity. I am not sure I fully understand this question in that the MCA specifically provides protection under Section 5 for decision makers. In so far as carers have to be consulted, this is clearly provided for in the MCA, the Code and in decisions from the Court of Protection which emphasises the importance of Article 8 of the European Convention of Human Rights. The starting point for decision making should be respect for the private and families lives of those concerned.

8. Has the Act ushered in the expected, or any, change in the culture of care?

31. In my opinion the answer is emphatically ‘no’. The MCA can be very empowering. As legal professionals, we are able to hold health and social services professionals to account. An example is the case where an elderly lady living on her own was removed by health and social services initially to hospital and then to what can only be described as a secure care home simply on the basis of best interests. I was brought in by a very concerned advocate and on me requiring them to assess her capacity, they discovered she had capacity to decide where she lived. Even then, they would not allow her to go home until a member of my staff and a friend of hers were dispatched to the care home for the purpose of allowing this lady to effect her wish to return home even if this was an unwise decision (the third principle).

9. Is there any evidence that the provisions of the MCA affect some groups disproportionately? If so, what data exists to compare representation across different socio-economic groups, Black and Minority Ethnic groups, and gender?

32. I do not feel qualified to express a view on this.

Decision Making

10. Are those directly affected by the Act being enabled and supported to make decisions for themselves to a greater or lesser extent than they would have been in the past? Does the means by which the decision is made – ‘general authority’, Lasting Power of Attorney, deputyship, Court of Protection – affect the quality of decision making?

33. I do not feel qualified to express a view on this.

11. What evidence is there that advance decisions to refuse treatment are being made and followed?

34. I do not feel qualified to express a view on this.

12. Has the MCA fostered appropriate involvement of carers and families in decision-making?

35. I have seen no evidence of this.

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13. Has the role of the Independent Mental Capacity Advocate (IMCA) succeeded in providing a voice for clients and an additional safeguard against abuse and exploitation for those who have no-one to speak on their behalf?

36. I would love to answer this question positively and there is undoubtedly some excellent work undertaken by IMCA’s. However this is statutory commissioned advocacy and is not to be confused with general advocacy. IMCAs are often excluded because of the role of family. This role may not always be positive and even where a family is loving and supportive, the views of P (which might be different) are can be stifled.

14. Has the level of referrals to IMCAs met expectations? What are the reasons for the regional variations in the number of referrals?

37. I do not feel qualified to express a view on this.

Are IMCAs adequately resourced and skilled to assist in supported or substituted decision making for people lacking capacity?

38. I suspect not.

Deprivation of Liberty Safeguards

16. Are the safeguards in the Deprivation of Liberty Safeguards (DoLS) adequate?

39. The simple answer is no. It is not possible to tinker with these to make them effective. They are fundamentally flawed. The confusion around the pivotal issue in respect of what is ‘restraint’ and what is ‘deprivation’ prevents a consistent approach to the human rights of those who lack capacity.

17. Are the processes for authorisation, review and challenge of DoLS sufficiently clear, accessible and timely?

40. As the whole notion of DoLS is not working effectively it must follow that the processes associated with it are also failing.

The Court of Protection and the Office of the Public Guardian

18. Are the Court of Protection and the Office of the Public Guardian sufficiently understood and accessible to all? Are they operating effectively and successfully?

41. Are they assessable to all, certainly not. In order to be accessible people need to be more aware of their roles and when to use them. They became less accessible when the Government decided that they should lose their own websites.

42. Are they operating effectively and successfully? The Court is slow, cumbersome, expensive and dominated by interpretations of the law. It must be simplified to be made...
more accessible. Having said that, many of the judgements are wise, thoughtful and assist greatly in an understanding of the MCA.

43. I note there are no questions about the Official Solicitor. They are clearly overwhelmed and in some cases feel they cannot take on the role of litigation friend. Who is then left to perform that task? This has not been thought though. We have worked very successfully with a number of IMCA’s but they are not commissioned to perform this task. Much more work needs to be done on this.

19. What has been the impact of the introduction of Lasting Powers of Attorney (LPA), especially with regard to decision making on matters of personal care and welfare?

44. I am concerned that there seems little focus on informing people who have capacity of their ability to plan for their incapacity. Whilst financial LPA’s are increasing, health and welfare planning would seem somewhat rare. Even when this is done, my experience is that health and social services do not understand the powers of the attorney and often have no effective mechanism for registering their existence. If you were to do one, where would you send it? This would seem to undermine the wishes of Parliament. Perhaps people’s lack of understanding is wrapped up in the misunderstanding of the ‘powers’ of the next of kin.

20. What concerns, if any, are there regarding the costs associated with registering an LPA, or with making an application to the Court of Protection?

45. A complex matter before the Court can cost each party in excess of £30000.

21. Is legal aid available and sufficient? What impact will the recent and proposed reforms to legal aid have?

46. The confusion around s.21A MCA is a problem. If a person appeals against their deprivation of liberty and they have funds that would normally mean that legal aid was not available, their legal aid is not means tested. However, if in the process of the proceedings the court wishes to determine best interests (which is part of the criteria for an authorisation) it is likely that the Legal Aid Agency will terminate legal aid thus frustrating the intention of Parliament.

Other legislation

24. How well is the relationship with the mental health system and legislation understood in practice?

47. Not very well. The two worlds do not coexist comfortably. This is partially the fault of the Government who had the opportunity of dovetailing both the MHA (amended 2007) and MCA (2005). This was not done. The courts have assisted e.g. GJ v The Foundation Trust (2009) EWHC 2972 (Fam) where Mr Justice Charles asserted the principle that the MHA takes precedence where it applies.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
48. In essence, rights under the MHA are well established and understood. In the case of C (by his litigation friend, the OS) v Blackburn with Darwen Borough Council & A Care Home & Blackburn with Darwen Teaching Care Trust [2011] EWHC 3321 (COP) 6.12.11 Mr Justice Peter Jackson stated:

35. In my view, there are good reasons why the provisions of the MHA should prevail where they apply. It is a self-contained system with inbuilt checks and balances and it is well understood by professionals working in the field. It is cheaper than the Court of Protection.
Single page summary.

It is important to distinguish the MCA (which on the whole is a well drafted and effective piece of legislation) with deprivation of liberty safeguards which is, frankly, chaotic, bureaucratic and contrary to the best interests of those who are ‘detained’.

The MCA is a good and well drafted piece of legislation which is poorly applied. This fundamentally undermines the rights of those who lack capacity and when poorly applied it can be used as a draconic tool of control people who lack capacity, or worse, people who are presumed to lack capacity where this has not been assessed. The checks and balances which are in the legislation are not applied because many decision makers (D) fail to understand or apply the process of decision making contained in the MCA. Many have never read either Code of Practice.

Fundamental problems which impede the effective implementation of the MCA are:

1. Lack of access to justice and human rights by those who lack capacity. How does the person who lacks capacity to make a particular decision at a particular time challenge either the finding of incapacity or the decision itself? How do vulnerable people access the potential protection of the MCA?

2. Impediments to seeking legal advice. The relationship between a solicitor and client is contractually based and if the person lacks capacity to enter into such a contract, strictly speaking they are left without the ability to seek legal advice

3. There is a misconception that only doctor’s can assess capacity (when in fact many doctor’s have never had any training on how to assess capacity)

4. There is a misconception that capacity assessments and best interest decisions bind staff (when of course the role of D is time and decision specific)

5. There is a misconception that the ‘next of kin’ posses decision making powers by virtue of being ‘next of kin’. This is constantly reinforced by health and social services who ask people who their next of kin is. Why?

6. Professionals seem to spend a lot of time at ‘best interests’ meetings. There is often little or no evidence that before best interest decisions are made, that the relevant person (P) has been assessed as lacking capacity. The first principle of the MCA is that all adults have capacity unless there is evidence they don’t. The term ‘best interests’ has become a holy grail and when a best interest decision is made by the best interests meeting that seems to bind subsequent action by professionals.

7. The most fundamental problem of all is linked to point 6 above. Health and social services professionals tend to make decisions by committee, whereas the MCA is about the individual responsibility of D.

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8. Problems are exacerbated by attempts by organisations to codify the MCA into operational procedures. This can have a stultifying effect. It can undermine the very principle that the buck stops with D and decision making is time and decision specific.

9. Because the word ‘mental’ is included in the title there is an assumption that you do not need to incorporate the basic principles of the MCA into practice unless you work in the world of ‘mental’.

10. The Court of Protection is slow, cumbersome, expensive, inaccessible and dominated by interpretations of the law. It must be simplified to be made more accessible like the Mental Health Tribunal under the MHA.

2 September 2013
EE – Written evidence

I write regards witnessing and experiencing how the Mental Capacity Act 2005 (MCA) is too badly drafted and so has ruined the rights of people with “mental disability”. Most people have an incapacity within the meaning of “mental disability”, not mental incapacity within the MCA.

In law, a mental disability can arise from a health loss of a year or more. The loss of mental functioning needs to be “not trivial” to meet the legal requirement of being “substantial” and so to be deemed a disability. A person with mental disability (such as those in hospital or in proceedings in Courts) need a much greater respect and careful approach for granting ‘reasonable adjustment’ such as more time, or more help, but where such people do ultimately have the capacity to make their own decisions

I am a highly able and articulate person with a chronic anxiety condition that in 2002 was deemed a disability within the meaning of the Disability Discrimination Act 1995 (DDA). I am being referred to, even by Lord Justices, as needing help under the Mental Capacity Act 2005. Yet that would be ludicrous for someone so able as myself, so that no help is available under the MCA or DDA, to mean that the MCA is a substantial step backwards to as good as totally take away the rights I had (and that were starting to work well) under the DDA.

Because the MCA is worded so badly to exclude mental disability, judges, lawyers and healthcare staff increasingly fully ignore the issues of mental disability.

An additional problem is that the Equality Act 2010, doing away with the DDA, suppresses recognition of mental disability also.

The MCA needs to be redrafted to explain the difference between mental disability and mental incapacity and the rights of both. That way older people in hospital, or care, or legal proceedings, that are able to make decisions, but have a mental disability (by being more a case of being worn out, than full mental incapacity), can be given the extra time and support to make those important decisions for themselves.

The same goes for younger people who are more mentally worn down or partly impaired with a mental disability but are wrongly referred to as under the MCA, to mean they lose their basic rights and lose their human rights because decisions are made for them.

Whereas under DDA the judges, lawyers, and healthcare staff should focus on respecting the person and their right to make their own decisions such as by asking what the person feels will help them make their own decisions. It follows that trying to impose on people with only a mental disability, the conditions and procedures of MCA, is highly improper. Stopping this highly improper conduct can only occur by redrafting the MCA to include “mental disability” and the DDA principles explained within a new MCA.

27 August 2013
Charlotte Emmett, Professor Julian Hughes, Professor John Bond, Dr Helen Greener, Dr Stephen J. Louw, Marie Poole and Professor Louise Robinson – Written evidence

Submission to be found under Professor Julian Hughes.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
We would like to submit the following to the House of Lords:

• Empowerment Matters response to the call for evidence.
• Empowerment Matters statement on the role of IMCA and Litigation Friend.
• Information about a collaborative research feasibility study with Cambridge University NHS Foundation Trust that we refer to in our response.

Who we are

Empowerment Matters is an ‘Advocacy and Mental Capacity Act Resource, Support and Information Agency’. We are a community interest company (social enterprise). We believe that people have a right to be involved in and at the heart of decisions that affect their lives and are committed to empowering and promoting the rights of individuals affected by the Mental Capacity Act (2005). Sue Lee and Jakki Cowley (directors of Empowerment Matters) have extensive experience as advocates, including Independent Mental Capacity Advocacy and in-depth knowledge and experience of the Mental Capacity Act and its practical application.

Jakki and Sue managed the IMCA Support Project at Action for Advocacy (a4a). During this time Sue and Jakki created a range of guidance on the Act for health and social care professionals and IMCAs which has been widely accepted and held up as national best practice amongst a range of professionals. Prior to Action for Advocacy both Sue and Jakki practiced as IMCAs and also managed two busy and successful IMCA services.

Sue is an experienced trainer and has delivered a range of courses on the Mental Capacity Act, trained IMCAs in their role and has provided courses on the Deprivation of Liberty Safeguards. Sue wrote the booklet ‘The Independent Mental Capacity Advocate (IMCA) Service’ published by the Office of the Public Guardian in 2007. Jakki contributes to various working groups producing guidance and standards relating to the Mental Capacity Act including the development of Guidelines on Prolonged Disorders of Consciousness with the Royal College of Physicians as well as NICE on the subject of dementia – quality standards of care and commissioning. Jakki is a member and on the committee of the Court of Protection Practitioners Association (CoPPA) and speaks at a range of conferences on the subject of Deprivation of Liberty and the Mental Capacity Act. Jakki was part of the Department of Health training team on the mental health advocacy qualification and has experience of delivering training on safeguarding, mental capacity, deprivation of liberty and advocacy.
Overview

The focus of our evidence is directed towards questions 1, 2, 3, 4, 7, 12, 13, 14 and 22. We have concentrated on the principles of the Act in terms of the implementation and current practice as well as the role of IMCAs and in particular what we’ve learnt from best interests decision-making involving IMCAs, development of the IMCA role, as well as the impact of the Act on the involvement of families.

1. To what extent has the Mental Capacity Act 2005 (MCA) achieved its aims?

We think it is fair to say that with the introduction of this Act came a recognition that for some organisations, a significant change in culture would be needed and that is something that cannot happen overnight. There is still much to be done to ensure that the Act is fully implemented in all sectors where it should be embedded in practice. Our experience is that many health providers in acute settings have not fully implemented the Act. There must be some examples of good practice in this area and it would be beneficial to share those with acute trusts who are finding full implementation of the Act challenging.

Our organisation trains staff working in social care and in health organisations and we provide training on the Mental Capacity Act that is delivered in-house to groups of staff, tailored to meet their specific learning needs. We realised some time ago that training on the MCA can only be truly meaningful if it is very explicitly related to the particular client group the participants on the course support or treat in their day-to-day work and the training must be very practical in its approach.

Our observations are that most of the people attending our courses have experienced some kind of training on the Mental Capacity Act. Almost universally they have picked up some knowledge and can, for example, quote the Act’s 5 principles and know that decisions can be made on another person’s behalf, however, it has become clear to us that it has been challenging for many of the participants to translate that previously acquired knowledge (theory) into using the MCA successfully in their everyday practice. The reasons for this are many but partly it is that the training they received did not demonstrate how they could do that (theory into practice) and also it is difficult if the organisation they work for has not incorporated the Act into their policies and procedures, care plans, recording systems etc or reviewed people’s care with reference to the Mental Capacity Act so that it is part of everyday discussions about providing care and support.

One of the 5 principles, namely, ‘before the Act is done or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive’, in our experience is commonly misunderstood or ignored. More work needs to be done on this by giving more practical examples, for example, how an older person on discharge from hospital could be supported to return home with support, adaptations or adaptive technology.

There is no doubt that the Act has encouraged providers to consider the rights of a person to make their own decisions but our experience is that sometimes the ‘presumption of capacity’ is followed without further enquiry when a person is perhaps verbally able to state want they want or can answer closed questions with a yes or a no but in actual fact further skilled discussion with the person can reveal a lack of capacity to make some decisions. It can leave the person in a vulnerable position, making significant decisions when in fact they

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lack the capacity to understand the implications of their decision. This could be clarified and include relevant examples should the Code of Practice be revised.

Another challenge is that the criteria for Serious Medical Treatment is causing confusion in health settings leading to a lack of instruction for IMCA where the duty to instruct exists. This is concerning as it means there are potentially many people who are entitled to the support and representation of an IMCA who do not get one (We will write more on this in the IMCA section).

We are currently undertaking a small research study on the use of IMCA in critical care situations and our early findings are that the SMT criteria is mis-understood or ignored because its application can be very subjective, i.e. what is considered serious treatment by one doctor is not necessarily considered serious treatment by another. An example of this is when I was an IMCA manager a consultant contacted me to say that he did not believe that a hip replacement would ever be considered a ‘serious medical treatment’ as it is so routinely performed and he did not think it appropriate to include it as an example in documentation on the IMCA’s role. However, as an IMCA provider, we did receive instructions where the treatment was for hip replacement indicating that the instructing doctors did consider it to be SMT.

• Sharing good practice in relation to implementing the MCA in acute settings would be very helpful.
• A review of MCA training, what works and what is now needed would assist implementation.
• Consideration should be given to training in Acute settings become a mandatory requirement.
• There are some examples of how the 5 principles work in the Code of Practice. More examples could be added, or further resources developed to enhance practitioners’ understanding of how to apply the principles in their own practice.
• The Serious Medical Treatment criteria for instructing IMCA urgently needs reviewing.
• There needs to be an organisation that takes the lead on encouraging organisations to share best practice and resources.

2 Which areas of the Act, if any, require amendment; and how?

We would ask that the following is considered for amendments:

• The role of 39d IMCA should carry an automatic referral to allow for IMCAs to introduce their role and how it may benefit either the person or their representative.

This is something the Department of Health recommended but does not occur in all local authorities. It could ensure there is streamlined practice rather than the variant that currently occurs. We know from research carried out by the Making Decisions Alliance that up to a third of RPRs are not even informed of their right to an IMCA. Current practice is that the supervisory body assess whether the person or their representative would benefit from the involvement of an IMCA (or the person/their representative feels they would but if many are not being informed of this right this is a concern). We believe advocates are best placed with explaining their role to the person or their representative rather than the
supervisory body as their independence from the supervisory body as well as their expertise on their own role can improve communication of information. This in turn could ensure better understanding of the Act and the DoLS by the person and their representative and ensures those wishing to access the CoP have the appropriate independent support and information.

- Best Interests Assessors should cross over geographical areas to remove the conflict of interest that many are faced with i.e. provide the BIA role in an alternative local authority to their usual full time job.

We do not feel it is appropriate or carries enough transparency if BIAs are making decisions about a DoL authorisation and working with colleagues who for example may be responsible for funding the outcome of a decision. Alternatively BIAs carrying out the BIA role for 1 day a week but then reverting to their usual role the rest of the week as this places them in a conflict of interests when they are responsible for making quite separate decisions but about the same person/home.

- We believe that the criteria of instructing an IMCA where there is ‘no-one appropriate to consult’ should be removed and that IMCAs should be instructed either when there is no family or friends or it is felt a benefit to the person to have IMCA involvement regardless of family involvement.

When family are deemed ‘appropriate’ it presumes that family and/or friends are suitably equipped with being able to advocate on behalf of the person. An IMCAs involvement is about independence and advocacy. Family and friends role is about feeding into the decision only and they are quite distinct roles. For example family and friends may have a very good relationship with the person but may not be able to represent them in meetings the way an independent advocate can. This is not a criticism of family members but a reflection of the fact that family/friends will always have their own issues and views on the decision similarly for professionals responsible for the decision. An advocates role is distinct from both of these and adds a safeguard and independent voice for the person, this aspect is missing if family and/or friends are deemed ‘appropriate’ as they would still feed into the decision the way ‘inappropriate’ family/friends do. Plus the word ‘appropriate’ means having to make a subjective judgment, which will vary across the board and places some people at an unfair disadvantage. It also assumes the Act would be fully understood by them or at least communicated fully by relevant professionals. Communication in this area cannot always be guaranteed and we believe that regardless, the independent element of an IMCA ensures that more robust decisions can be made and reduce the need for mediation (which is recommended by the Act albeit does not really exist in practice) and/or complaints.

- The specific decision element of where IMCAs should be involved should be widened to encompass other decisions that are made about people that lack capacity.

The role of an IMCA is short term but decisions about a person who lacks capacity are often ongoing. We believe that IMCAs play a crucial role in many decisions and limiting their required involvement to just two distinct decisions means there may be no advocacy involvement for what is probably the most vulnerable client group. We’ve seen from Department of Health statistics that the demand for IMCAs in safeguarding is higher than treatment decisions yet it is a discretionary role and therefore limited or less of a priority in

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terms of resources. Ultimately IMCAs have to prioritise treatment or accommodation decisions as this is a statutory role yet the need for IMCAs in other decisions is demanded.

3 At the core of the MCA are its principles and definitions of capacity and best interests. Are these appropriate?

The principles are sound and are at the heart of the intention of the Act. The problem lies in the translation of those principles into practice which is not an easy thing to do. The Code of Practice does give some examples but information on the principles and more examples related to particular client groups need to be available. Training on the MCA must show how people to apply the principles consistently to every person they support or treat.

The principles and the explanation of how to work out best interests is clear in the Act and explained well in the code of practice. We have learnt much about good practice when making best interest decisions over the past 6 years and we know that it can sometimes be a very complex process, requiring the balancing of many different factors. The examples in the code of practice are fairly simplistic and it would be beneficial to further enhance that information with other more complex case examples. To assist best practice, more examples of recording best interests decisions would be helpful.

4. To what extent have the five principles of the MCA been implemented in frontline practice? What evidence is available to assess this? Is there a satisfactory balance between enablement and protection?

We know from the CQC DoLS report of 2012 published in February of 2013 that the implementation varies in particular between health and social care. We know from the DH IMCA annual reports that the instruction of IMCA varies widely, even in geographical areas that have a similar make up in terms of numbers of people and NHS Trusts – this suggests awareness is better in some places.

We also know from data gleaned from the FOI Act that the number of DoL authorisations varies quite significantly across the country. All of this data suggests the implementation has not been fully successful and we feel this needs to be addressed.

The Mental Health Foundation along with Norah Fry Research Centre at Bristol University are currently awaiting an outcome on a recent grant application for a mental capacity collaborative 3 year project with a range of organisations to promote best practice and to address the issues around lack of awareness of the Act. It is our view that this project is very much needed.

Many of the cases that reach the Court of Protection (that are published) highlight that many decisions taken on the ground veer on the side of protection rather than enablement and in turn these decisions are often then changed in court judgements. The Neary judgement being just one example:


The Court represents only a sample of current practice but it would be reasonably safe to hypothesise that protection leads the way for many decisions often due to the fact risk is a
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5. How effective was the Government’s implementation plan? What measures were taken to ensure that professionals and families of those who lack capacity know about and act in accordance with the provisions of the MCA? Has it led to sustainable change?

We have concerns that the implementation plan did not focus specifically on the general public and whilst there were online resources for family/friends or the person themselves they were very much reliant on being informed by a professional or alternatively finding themselves in a situation that meant they went out and searched for relevant information on the MCA. As such we believe that this information is predominantly held by professionals and family and friends/the person themselves are still not being given direct information about their rights or the Act and how decisions are made unless they specifically ask.

We know that knowledge amongst professionals varies quite widely from our own work as IMCAs, as trainers working with family/other professionals and through our work both at Action for Advocacy and Empowerment Matters where we receive a number of queries about elements of the Act. This has led to some change in knowledge and awareness for those that are within the framework of decision making under the Act on a regular basis, for example having a family member with a learning difficulty who might be having several decisions made on their behalf. However for those that have capacity or have a family member that suddenly loses capacity, through a brain injury or stroke for example they are still not aware of this vital and important Act. We believe the government needs to ensure that awareness raising is supported and funded.

12. Has the MCA fostered appropriate involvement of carers and families in decision-making?

Our organisation is aware that the level of information offered to families and carers in the decision making process is not thorough enough to give them a grasp of how decisions are made and what their involvement should and can be. In our role at Action for Advocacy we received a great deal of enquiries from families going through the decision making process that involved a loved one and basic information such as what does capacity mean or how does the assessment of capacity compare to the fact that someone can still express a view. This lack of communication and thorough exploration of whether families or carers have understood the process is a concern. This has led to us delivering training specifically for family carers on the Act but we recognise this is just a small step towards raising awareness of the Act. The training has been well received by family carers who before the training were totally unaware that the Act existed or what their rights are as well as those of their family member.

The Act appears to have created a culture of ‘them and us’ by which we mean professionals as decision makers who have to come to a view as to what is in a persons best interests may not always see the role of families as a vital one. There is also the element that family is not...
Empowerment Matters CIC – Written evidence

always about who a person is related to - friends, neighbours, local communities need to be included (confidentiality protected where necessary of course) in order to create a picture of the person and their wishes as well as the impact of a decision on families. The Act makes clear that a decision is about P and not what is in the best interests of those around them. However P needs to be seen as being part of a wider circle of decision supporters (a practice that is more recognised in parts of Canada). For example a patient has an interest in recovering from their illness or in determining what the best course of action is, but so do those around them, family, carers, friends. Sometimes these various interests can be independently specified, but in other cases they are inextricably intertwined (this is from a submission from the Essex Autonomy Project made to the BMJ about changing the way a best interest decision is described in the Act). The Act needs to recognise this by remaining clear that the decision is about P but cannot at all times be made independently of the best interests of others.

Carers and families are often not made aware of their rights, are treated as if next of kin has a legal basis which it doesn’t and/or this is not explained to them when they believe they have specific rights of decision making.

We also know that IMCA services are approached to be involved when families are disagreeing with a decision that is about to be made. This strikes us that there is a balance of tension between those that make decisions and family who feel they are not being heard.

• A review of training on the MCA that is available to family carers and what the need is should be undertaken

• Training on the MCA should be widely available to family carers

• MCA training for professionals should specifically include elements around communicating with friends and family about how best interests decisions are made and the family’s involvement.

13. Has the role of the Independent Mental Capacity Advocate (IMCA) succeeded in providing a voice for clients and an additional safeguard against abuse and exploitation for those who have no-one to speak on their behalf?

There is no doubt that IMCAs provide support and representation for many people who have absolutely nobody else who can speak on their behalf. The role of the IMCA as a non-instructed advocate, if carried out in the way the legislation intended, is a valuable safeguard for people who would otherwise have no ‘voice’ when really crucial decisions are being made about their lives.

We fully appreciate the importance of identifying best practice, solutions and recommendations. In order to do that, it is necessary to have an understanding of the issues. Here’s a very quick summary of some of the challenges to IMCA involvement in SMT/EoLC and DNACPR decisions.

• Confusion about the SMT criteria generally and specifically how they apply to DNACPR and EoL decisions.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
• A lack of training on MCA in acute settings. In general, e-learning appears to be the norm which does not seem to adequately prepare clinicians for consideration of IMCA involvement.
• Training is often generic and does not prepare staff for the practicalities of MCA implementation within their particular specialities.
• Linked to above, many misunderstandings about the IMCA role prevail. Two examples are that IMCAs take too long to get involved and that they always agree with the proposed decision. Mostly these seem to be based on their perceptions rather than their experience.
• Processes/forms to prompt clinicians to consider IMCA involvement may not be in place.

It’s interesting to look at what’s in place in Scotland and Wales and to consider if there’s anything to learn from the way they approach SMT/DNACPR. The Adults with Incapacity Act in Scotland says that certain health professionals can issue a ‘Certificate of Incapacity’ which states that the person is incapable within the meaning of the Adults with Incapacity (Scotland) Act 2000 in relation to a decision about specific medical treatment. Whilst we are not suggesting that this is what should happen in England, it is interesting that in order to be a ‘certificate provider’, health professionals must undertake mandatory training and if a certificate is provided by a person who has not done the training, it renders the decision illegal. We suppose the nearest equivalent in England is the consent form, for example, Cambridge University Hospitals NHS Foundation Trust use ‘Form for adults who lack the capacity to consent to investigation or treatment’. Section C of that form asks the clinician completing the form to consider a referral to IMCA but without training it would be very difficult to know whether the duty to refer exists.

Similarly with DNACPR forms we can look to Wales. In England there isn’t a national DNACPR form. Some areas such as NHS East of England (that was) introduced a standard form which some NHS Trusts within the area have adopted. Some Trusts prefer to use their own in-house forms. Invariably they do not seem to make any reference to IMCA from what we have seen. Wales has developed the ‘All-Wales DNACPR form’ and one of the considerations on the form is a statement to tick under ‘best interests’ which says: ‘This has been discussed and agreed with the patient’s next of kin/proxy’ and a note refers to proxy as either IMCA, LPA or CAD. Development of a national All-England DNACPR form could be very useful.

EoL assessment and care planning.

Where IMCA involvement works well, there is a prompt to involve IMCA at the assessment and care planning stage. Some areas seem to have incorporated prompts and guidance re IMCA into their assessment documents and this enables IMCA to be involved at an early stage. This is vital because it is at this point that decisions will be made about treatment/DNACPR etc that should take into account the person’s views, wishes, feelings etc as well as a whole range of other factors such as cultural, religious, spiritual, values etc considerations. There is sometimes an issue with EoLC decisions not being seen as SMT.

Research into IMCA involvement in ICU

Please bear in mind that this is a small study. One of our early findings from the research is that clinicians in this area are unlikely to see the benefit of involving an IMCA. When they do
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Best Practice on IMCA involvement in End of Life Care example (based on an actual case but anonymised)

Joanne is 58 and has Down’s Syndrome. She has lived in the same care home for the last 25 years. She has been diagnosed with terminal cancer and has had a diagnosis of dementia for over 2 years. Joanne has opted not to get out of bed for the last 3 weeks despite lots of encouragement. Joanne was admitted to hospital with pneumonia and whilst there the Specialist Palliative Care Team got involved. Their role is to work with patients to achieve the best quality of life for any patients with a life-limiting illness. Whilst assessing Joanne’s care needs and planning for her end of life care, prompts on the assessment documentation indicated that a referral to IMCA was needed. The SCPT had received MCA training and were alert to the possibilities of IMCA instruction. This was particularly crucial as the multi-disciplinary team responsible for planning care were not in agreement about whether or not it was in Joanne’s best interests to return to the care home. Some members of that team felt that is was appropriate for Joanne to move to a nursing home. This was a complex case involving several SMT/EoL care/DNACPR decisions as well as a decision about a change of accommodation. The IMCA was able to support Joanne to find out her views and to represent her in multi-disciplinary meetings when decisions were being made. The IMCA stayed involved as new decisions were occurring regularly. Joanne did return home from hospital, was supported by people who she knew very well in conjunction with specialist nurses and died at home 3 weeks later.

Recommendations to support appropriate and timely IMCA instruction in SMT/EoLC/DNACPR decisions

• Mandatory MCA training which is client/team specific that particularly supports implementation in the area staff are working in, offering practical solutions and implementation advice. Our training has shown that good results can be achieved through focusing on practical application of the Act in everyday practice and practical assistance with forms/guidance etc. for staff.
• Documentation that offers relevant prompts and guidance on when IMCA must be instructed.
• Standardised forms such as DNACPR forms could be helpful.
• Clarification on SMT criteria, possibly through revision of the Code of Practice (and possible removal of the ‘serious’ part of the criteria to make IMCA support available to any person who lacks capacity to make a particular treatment decision)
• Clarification of why DNACPR and some EoL decisions are SMT decisions and therefore duty to instruct IMCA exists.
• It may be appropriate to instruct an IMCA at any time in the end of life care planning process but it is particularly relevant at the assessment and care planning stage. Work could be done to promote this message.
• As GPs are often involved in DNACPR orders in care homes, more needs to be done with specific training. CCGs have a vital role to play in this – perhaps IMCAs could be involved?

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• ICUs need to be targeted with specific information about why MCA training is relevant and vital with specific examples about IMCA instruction in that environment and the benefit of involving IMCA.
• Good Practice is that specific forms in acute settings are available for staff to complete when people lack capacity to consent to particular treatment. The forms could make it clear that DNACPR is a decision IMCAs must be involved in (if nobody to consult etc). If they contain a prompt to instruct IMCA and staff are MCA trained, this works well and instruction is more likely to occur. There needs to be a way of ensuring that all Trusts have done this work and are using them regularly.
• CQC should have a role in monitoring whether appropriate instructions to IMCA have been made.
• Consideration should be given to extending the role of the IMCA to be similar to the 39d IMCA role so that when family & friends of a person that lacks capacity feel they need support to represent their family member effectively, that support can be given.

Limitation of the IMCA role

The person’s voice cannot always be represented due to the restrictions on the IMCA role with respect to the limited decisions they can be involved in and the reality is that advocacy services are not always able to provide advocacy where the advocates are fully trained on non instructed advocacy or the MCA.

The Act promotes advocacy where the criteria of an IMCA is not fulfilled but this becomes meaningless if advocacy services do not have sufficient funding to train their staff to the appropriate level of skills and knowledge. Alternatively the financial climate may mean there is no funding in a local authority to commission and therefore provide an alternative advocacy service.

Similarly the Act promotes mediation when family disagree yet the only mediation that exists is often within a legal context and is costly. IMCA services are often asked to be involved in these cases because of the lack of mediation/alternative advocacy services. Some IMCA services accept these instructions although technically according to the Act they shouldn’t as the Code is quite clear that disagreements are not a reason to instruct an IMCA. Those services that do not take this type of instruction are wrongly criticised despite the fact that they are following the Code.

This is an area that needs exploring further and the role changed to possibly reflect that it is beneficial to instruct an IMCA where family disagree or feel unequipped to fully represent their family member due to lack of knowledge of the Act. This in turn, whilst requiring an increase in resources, in the long term could reduce the volume of cases that go to the CoP which can be a lengthy and costly experience.

14 Has the level of referrals to IMCA met expectations? What are the reasons for the regional variations in the number of referrals?

The level of referrals has increased steadily since 2007. The expectation outlined in the Regulatory Impact Assessment for the MCA was that 6,000 instructions for serious medical treatment would be made in England every year. In 2007-2008 728 instructions were made (DH annual IMCA report) and in 2011-12 1,743 instructions. It is encouraging to see an increase in SMT instructions but it is concerning to see that the overall instruction for SMT in order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
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is much lower than anticipated. 1,743 receiving the support and representation of an IMCA in the whole of England would seem a large under-representation.

The total number of instructions for SMT for 2011-12 is very similar to the number of instructions for care reviews where there is a discretionary power to instruct. IMCAs report that they are often instructed for an accommodation decision by a social worker where the person is in hospital and there is a decision to be made about future accommodation but there has not been an instruction for the treatment decision that was the reason for the person being in hospital originally. It may be possible of course that a person may lack capacity to make a decision about their accommodation but have capacity to make the treatment decision; however our experience is that this is often not the case and the need for the IMCA instruction for the treatment decision has not been picked up by the clinical team.

In 2009 when we were IMCA Support Project Managers at Action for Advocacy we set up a working group to explore reasons why instructions for SMT were low. Year 2 data from the Department of Health revealed that 74 IMCA providers had received 6 SMT instructions or less in one year and a high percentage of these received no SMT instructions at all. One of the issues identified was that the Code of Practice says that ‘...the Act imposes a duty on the NHS body to instruct an IMCA’. There was much confusion about who actually instructs the IMCA in the hospital. We wrote guidance 47 to provide some clarity on this as it appeared that many IMCA providers as well as clinical teams were of the impression that only a doctor could instruct as this had been their interpretation of the Code of Practice. It is still likely to be the case that some hospitals are not organised in terms of when, who and how instructions to IMCA are made. Doctors may not have had any formal MCA training.

The CC v KK48 case has implications for IMCA providers in SMT instructions as well as change of accommodation instructions. The IMCA will need to consider alternative options and an assessment of capacity should not be carried out until the person that lacks capacity has detailed information about the proposed decision. IMCA should therefore be involved at an early stage when it is thought that the person may lack capacity to make the particular decision. This could be clarified in the code of practice.

One way to address the confusion around the Serious Medical Treatment criteria would be to change the Act to NHS bodies having a duty to instruct IMCA for a person that lacks capacity to make a decision about medical treatment and remove the ‘serious’ part of the criteria. That would be much clearer and would not require a subjective assessment of the seriousness of the proposed treatment. We know that an adult that lacks capacity to make a medical decision is extremely vulnerable in a hospital setting and this would ensure that an independent person is involved, regardless of the treatment proposed. In addition to that, if the person that lacks capacity is supported by family and friends, they should be given a

47 The Involvement of Independent Mental Capacity advocates in serious medical treatment decisions. Action for Advocacy, 2010

48 CC and KK v STCC EWHC 2136 (2012)
choice about whether or not they would want the support of an IMCA, similar to how the 39d IMCA role works in the DoLS. What some of the stories about the people in Mencap’s ‘Death by Indifference’ report tell us is that some family members felt so helpless when they were at their loved one’s bedside and felt that they couldn’t influence the decisions being made. The support of an IMCA could make a considerable difference to the individual and their family in that situation. There are of course resource issues but the overall benefits to the patient, their families and the NHS could be considerable.

If you consider a scenario where a person who has a learning disability, lacks capacity to make the treatment decisions, is ‘unbefriended’ and has the support and representation of an IMCA who is spending time to get to understand the person’s views and is asking questions to seek information on the proposed treatments, is checking how the decision is being made and that the person’s rights are being upheld. In the next ward is another person who has a learning disability and has elderly parents. They are concerned about his welfare but are totally unaware of the MCA and best interests decision-making and are struggling to keep up with what the doctors are telling them. Isn’t the person without an IMCA significantly disadvantaged in this situation?

The Regional variations in the number of referrals could be down to a number of factors. In the early days of IMCA, it was expected that IMCA providers would have a role in promoting the service and the Act in general. Commissioning arrangements for many providers now would mean that the expectation is that they focus on providing advocacy and that their previous ‘ambassador’ role is not now funded. Indeed, as some organisations work on a zero hours type of contract, there is no scope at all for additional promotional work. IMCAs cannot be expected to be solely responsible for IMCA awareness in their local authority area. It is important that commissioners understand the role of IMCA and know what service users should expect from a quality IMCA provider. To assist with this, we are devising a checklist to support commissioners in identifying quality IMCA reports that conform to established best practice and guidance.

Many Local Authorities have very effective MCA leads that liaise with organisations across their area and have established links with health colleagues. They take a pro-active approach when considering implementation issues and have a crucial role in ensuring MCA implementation across their areas. We do not know how well they are resourced but we would suggest that adequate resourcing of these fundamental roles and supporting teams is crucial. They have a very useful role in raising awareness of the MCA and IMCA and also providing advice and guidance on the Act to front-line workers.

It is concerning to us that there doesn’t appear to be any organisation that has the responsibility of monitoring MCA compliance and IMCA instruction. It should be part of monitoring care home provision against the national standards. It would be relatively easy to measure MCA compliance against existing standards. If the MCA has not been implemented in a care home, staff may be quick to presume a lack of capacity, not involve service users in decision-making appropriately, will not be looking for ways of maximising a person’s capacity or making robust best interest decisions or referrals under DoLs and will not recognise when a person is eligible for IMCA (not their responsibility to instruct but they should know entitlement to IMCA). This is clearly not acceptable and when that happens there should be a way for CQC to indicate that minimum standards are not being met.
Equally in hospitals, there must be a way of monitoring MCA compliance and IMCA instruction across each hospital. Having access to IMCA when you are entitled to it should not be a ‘lottery’ as it is now. It is very dependent on whether the staff have been trained, whether there is an MCA lead in the hospital and whether documentation prompts staff to consider IMCA.

Our experience in carrying out a small research study on the use of IMCAs in intensive care environments is that there are many ‘myths’ about how IMCAs operate (such as they always delay treatment decisions) what their role is, and perceived difficulties of contacting IMCAs are getting IMCAs to come into the hospital. Some of this is due to inadequate MCA training.

There is no longer a national up to date database that lists all IMCA providers in England. Our understanding is that no funding has been made available to do this. This leads to delays in instruction if the client needs a different IMCA service. NHS intranet systems make it very difficult for IMCAs to be able to put this information on to NHS websites so hospital staff are reliant on a colleague knowing who to contact and how. We believe that commissioners should have a duty in ensuring that the IMCA service they fund is publicised either by them or that the IMCA service is funded to enable them to carry out training across the board, including leafleting. Commissioners are failing in their duty if they merely fund the provision of a statutory service but do not enable the service to promote their work. They have a duty to ensure that vulnerable people that have a right to an IMCA have the best chance of getting that independent representation.

- Local Authority MCA teams do much work to ensure that MCA implementation is effective in their local area. They should be properly resourced to further that work.
- A review of the challenges that prevent hospitals from instructing IMCA needs to be undertaken followed by an agreed action plan to support thorough MCA implementation.
- CQC should have a role in monitoring whether appropriate instructions to IMCA have been made in hospitals.
- Serious consideration should be given to changing the SMT criteria to make IMCA more available to people that lack capacity to make treatment decisions and their families.

22. Is the role of the Care Quality Commission in inspecting on the MCA standards adequate and appropriate? Is there a case for additional powers?

The CQC themselves acknowledge that they do not have enough knowledge, skills or experience with regards the Act which clearly has a huge impact on their ability to inspect the relevant sites that come under their responsibility. Most recently they advertised for specialist advisors to support them in all elements of their role and both Directors of Empowerment Matters applied for these posts (separately but in the area of mental capacity) but they have put the recruiting of these posts on hold for the

50 A feasibility study on independent mental capacity advocate involvements in critical care units. Partnership between Empowerment Matters and Cambridge University Hospitals Trust/University of Cambridge
In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.

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time being due to the recruitment of ‘patient/expert by experience’. This decision it would appear to us does not enable them to inspect more adequately or appropriately (on this particular specialised area).

An organisation’s policies or procedures unfortunately does not convey their practice or culture of care and we have seen this reflected in the numerous reports that highlight bad practice and abuse of vulnerable adults. The CQC are the only organisation overseeing a range of hospitals and care homes and as such should be adequately equipped when inspecting. The MCA is intended to safeguard vulnerable adults, it also introduced a new criminal offence that means if a person that lacks capacity is willfully neglected or ill treated then professionals responsible for their care who carry out that act can subsequently be prosecuted. The CQC therefore should use their powers of closure of an organisation, for example, to ensure that there is greater protection for vulnerable adults. We do not feel the powers of inspection sufficiently cover the needs of protection and empowerment, for example analysing whether best interests decision-making processes are as robust as they should be.

CQC are in a unique position of being able to meet with patients in hospital or residents in a care home. If there was an advocate involved in this process to support someone to have their voice heard and feed into the process then this could enhance the inspection by ensuring residents/patients are integrated more given it is the care they receive that is being inspected. Inspections should not be carried out through only consulting staff or residents that have capacity as this means the most vulnerable are not listened to. CQC should be speaking to and involving advocates, or a person’s family, friends or informal carers to contribute to the inspection as well as supporting the person that lives in the particular environment

• CQC inspectors should be adequately skilled to enable them to identify when the MCA has not been implemented to a satisfactory standard within a care or health settings
• The regulatory framework should cover MCA implementation in care and health settings
• CQC should have the power to act when the MCA has not been satisfactorily implemented in a hospital or care home.
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Empowerment Matters CIC is working in partnership with Cambridge University Hospitals NHS Foundation Trust on a small research study. The title of the study is:

‘A feasibility study on Independent Mental Capacity Advocate involvement in critical care units’.

Background:

In September 2011 a Wellcome Trust sponsored multi-disciplinary symposium involving key experts in the field discussed the challenges of decision-making about medical treatment on behalf of individuals with severe brain injuries. The symposium partly focussed on whether the Mental Capacity Act had been incorporated into clinical practice and whether information about the patients’ prior values and beliefs were routinely considered when best interests decisions were being considered. The event’s presentations can be viewed online: http://www.cf.ac.uk/jomec/contactsandpeople/profiles/kitzinger-symposium.html

One suggestion highlighted as worthy of further exploration was the idea that Independent Mental Capacity Advocates [IMCAs] might usefully have an expanded role to support some ICU contexts. The suggestion was that IMCA ‘clinics’ might be the most appropriate format via which to deliver such a service.

The definition of Serious Medical Treatment set out in the Mental Capacity Act 2005 [MCA] means that many patients treated in ICU will be subject to ‘best interests’ decision-making (Menon and Chatfield, 2011). The MCA makes it clear that in order to act in the ‘best interests’ of a patient it is important (if possible, practical and appropriate) to consult with family or friends. If the individual does not have anyone to help represent them, or if family are deemed not ‘appropriate to consult’ (MCA Code of Practice 10.42), then there is a duty on NHS bodies to instruct an IMCA.

At the symposium it was recognised that IMCAs could potentially have a useful role within the ICU even where ‘appropriate’ family members are present – especially when disagreements arise or when the family feels unable to represent their loved one effectively. ICUs are places where serious medical treatment decisions are routinely made on behalf of incapacitated patients (many of whom will never regain capacity e.g. those with serious brain injuries). Families may lack awareness of the Mental Capacity Act and how decisions should be made when a person lacks capacity to make treatment decisions. ICUs are places where family, albeit ‘appropriate’ in every way, may be unprepared or unable to represent their loved one due to the extreme and, often sudden, change in circumstances or due to the way in which clinicians might practice in these settings.

Some clinicians reported their experiences of IMCA involvement when patients did have family and described situations where communication between clinicians and family had become difficult and in those situations IMCA input had been of benefit and in some cases may have influenced a decision by the family not to proceed with a complaint. Many of those present at the Symposium, which included a variety of professionals from different backgrounds, felt that an exploration of IMCA involvement in ICU, particularly whether IMCA ‘clinics’ would be useful to clinicians, families and if improved best interests decision-making was an outcome, ultimately it would be beneficial to the patient.

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The hypothesis was that IMCA involvement might lead to better compliance with the MCA, better communication, and improved decision-making, at least in some cases. It was also suggested that this could be cost-neutral when balanced against the cost of inappropriate decision-making (not least because of the costs of subsequent complaints).

Professor Jenny Kitzinger (Cardiff University) and Professor Celia Kitzinger have conducted in-depth interviews with families of severely brain-injured relatives, exploring families’ experiences of decision-making. Initial findings based around 100 hours of interviews suggest that families may leave ICU unaware of how best interests decisions should be made, and without any recall of being asked about their loved one's own wishes. Several families who participated in this study felt strongly that they had been unable to represent their loved one effectively and/or that clinicians had made treatment decisions which disregarded prior expressed values and beliefs. Most were unclear how, if at all, their loved one’s prior expressed values and beliefs had been factored into best interests decision-making in ICU.

A key question for the study is:

**Would IMCA ‘clinics’ work in practice? If so, how might they best be organised, what benefits might they have and what are the resource implications?**

**The IMCA Service**

NHS bodies must instruct an IMCA when decisions about serious medical treatment are being made where the person lacks capacity to make the particular decision and there is no one appropriate to consult, other than paid carers, about whether the decision is in the person’s best interests. Serious medical treatment is defined as treatment which involves giving new treatment, stopping treatment which has already started or withholding treatment that could be offered where:

- If a single treatment is proposed there is a fine balance between the likely benefits and burdens to the patient and the risks involved
- A decision between choice of treatments is finely balanced, or
- What is proposed is likely to have serious consequences for the patient (MCA Code of Practice 10.44)

Serious consequences are defined in the MCA code of practice as those which could have a serious impact on the patient either from the treatment itself or due to wider implications and may include, for example, treatments which:

- Cause serious and prolonged pain, distress or side-effects or
- Have potentially major consequences such as stopping life sustaining treatment or amputation or major surgery or
- Have a serious impact on a person’s future life choices

Once instructed by an NHS body, IMCAs have a specific role and responsibilities.

*An IMCA is a statutory advocate and their responsibilities are laid out in both the Act and the Code of Practice however the basis of the role is to advocate on the person’s behalf, that is to promote their rights, ask questions on their behalf, obtain information pertinent to the decision, suggest*
alternative courses of action where they believe these reflect the person’s wishes and feelings and conclude this by submitting a report to the decision maker that articulates their findings as well as providing representation on the person’s behalf about the decision. (Lee & Cowley 2011)

IMCAs have expert knowledge on the MCA and best interests decision making and it is commonly accepted by the profession and other stakeholders that part of their role involves educating health and social care professionals and carers (both paid and unpaid). This part of their role, although not acknowledged or anticipated formally within the Act or the Code of Practice, has become a valuable part of the IMCA role.

Research into the impact of the IMCA service (Townsley and Laing 2011) highlighted that:

‘This research showed the role that IMCAs played as educators and disseminators of important information, both formally through the delivery of organised training sessions and informally, by modelling good practice and providing ‘on the job’ support and information about various aspects of policy and practice.’

The research also highlighted that IMCAs can have a significant impact when best interests treatment decisions are being made:

‘Twenty two SMT cases were represented in this research. In 60% of these (n=13), IMCAs felt their involvement in the case had made a difference to the outcome of the decision, or the timing of any subsequent treatment. The data collected showed evidence of the IMCA role in bringing a holistic, person-centred angle to the clinical decision-making process, particularly in terms of bringing new information to bear on the case and helping to broaden clinical thinking about how adjustments could be made to the treatment to reflect the person’s needs and wishes. In some cases, this meant that different decisions were made about people’s treatment involving a different treatment being given or no treatment given at that time.’ (page 8)

Detailed information about the involvement of IMCAs in serious medical treatment decisions is given in the Action for Advocacy Best Practice Guidance for Healthcare Professionals and IMCAs (Lee and Cowley 2011)

The IMCA service is in its 6th year and data from the Department of Health would suggest that the number of instructions from NHS bodies for patients where serious medical treatment decisions are being made is much lower than originally anticipated (evidence from the Department of Health IMCA Annual Reports years 1, 2 & 3 and the government’s Regulatory Impact Assessment in 2006). Action for Advocacy carried out some work with a serious medical treatment (SMT) working group in 2007 which attempted to understand the reasons for the low number of SMT IMCA instructions and concluded that many NHS Trusts had not fully implemented the MCA resulting in a lack of knowledge about the Act in general and particularly about IMCA.

We do not have any data about how many instructions to IMCA are made from ICU but it is reasonable to assume given the data we have on some treatments, for example only 74 IMCA instructions for patients lacking capacity to make a decision about major surgery were made in total throughout the country in year 5 (2011-2012), that not all patients eligible for IMCA whilst in ICU are referred. Additionally there is anecdotal evidence that IMCAs are

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sometimes involved when patients have families and it would be useful to have some data on when and why this is happening and the perceived benefits of this.

**Aims and objectives of the Research**

The aim of this research is to investigate and deliver evidence on whether there could be an expanded role for IMCA via the provision of IMCA ‘clinics’ within ICUs.

To achieve this aim, the research will be structured to meet the following key objectives:

1. To produce an overview of the current statutory role of IMCAs specifically in ICU situations to find out:
   - how many instructions there are nationally for IMCAs in ICUs
   - how many instructions from ICUs per Acute Trust in England
   - how IMCAs are practising in ICUs
   - what types of cases they are instructed for
   - the specific nature of their involvement

2. To carry out a small scale qualitative interview study in 2 sites involving interviews with IMCAs, with clinicians and with families who have a range of experiences within ICU. The purpose of these interviews is to ascertain:
   - When do clinicians consider consulting an IMCA? For example, what circumstances, what time of day or night?
   - When might families consider consulting an IMCA?
   - What do IMCAs, clinicians and families see as the benefits/pitfalls in involving IMCAs?
   - How would IMCAs view the possible provision of IMCA ‘clinics’ in ICUs?
   - What training and/or support would IMCAs need if such ‘clinics’ were provided?
   - If IMCA ‘clinics’ were to be provided, how do IMCAs/clinicians/families see them working on a practical level?
   - What would be expected of an IMCA and is this more than/different from what they can deliver?
   - How would any concerns expressed by clinicians about the involvement of IMCAs be addressed?
   - What are the resource implications for IMCAs/ICUs?
   - How would IMCAs work to best practice in their role within ICU?
   - What kind of information (eg leaflet) would be needed about the IMCA service?

If the initial scoping exercise suggests that widening the IMCA role within ICU and the provision of IMCA clinics might improve decision-making and compliance with the MCA the plan would be to seek further funding for a pilot delivery of such a service.

**Outcomes**

The research will:

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• Map the extent to which IMCAs are currently working in ICUs and whether that includes cases where the client has family.
• Ascertain views from clinicians, IMCAs and families on whether IMCA ‘clinics’ would potentially be of benefit.
• Ascertain if the views from the various stakeholders indicate that widening the IMCA role within ICU might improve decision-making and compliance with the MCA and consequently reduce dissatisfaction and complaints.
• Ascertain if seeking further funding for a pilot delivery of IMCA clinics and evaluation of such a service is viable.
• Raise awareness of the MCA in ICUs through the research and through publication of the project report.

Current position

We have interviewed some clinicians and IMCAs on one site and are about to start interviews on the second site.

Early findings appear to indicate that:

• The criteria for SMT and instructing an IMCA are challenging to interpret and can be a barrier to IMCA instruction.
• Clinicians working in ICU may not be able to access MCA training other than e-learning.
• The IMCA role is not well understood.
• Clinicians in ICU are more likely to instruct an IMCA for some patients who lack capacity when a decision is about the withdrawal of life-sustaining treatment or when there is a dispute with the patient’s family.
• Some clinicians and IMCAs feel that an IMCA ‘clinic’ would be beneficial to families and the patient.
• Some IMCAs feel that the provision of IMCA clinics would be outside the scope of their role.
• Feedback from IMCAs is that most have had cases in ICU where family members are involved.
• IMCAs judge the MCA knowledge of the ICUs where they have worked as mostly average or poor and some are described as having excellent or good knowledge. We hope to be able to report fully on our findings by April 2014.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Background to this response

1. This document has been produced following a series of seminars in conjunction with Irwin Mitchell Solicitors and Thirty Nine Essex Street Chambers for IMCAs and other professionals that work in this field including best interests assessors, MCA/DoLS leads, IMCA commissioners and local authority solicitors.

2. The focus of our evidence is directed towards questions 13, 15 and 18. We shall concentrate on the role of the litigation friend and the extent to which IMCAs could and should perform that role in light of the law, guidance, and the practical difficulties surrounding Court of Protection proceedings.

The role of the Official Solicitor as Litigation Friend

3. If a party to Court of Protection proceedings lacks litigation capacity, they must have a litigation friend: Court of Protection Rules 2007 r.141(1) (‘COPR’). The Court may appoint the Official Solicitor or some other person to undertake this role: COPR r.143(1).

4. The Official Solicitor issued a Note (here) in February 2012 which stated:

(a) OS has “reached the limit of his resources with regard to Court of Protection welfare cases ...”
(b) “As a result of this development the Official Solicitor is unable to accept invitations to act in any except the most urgent cases...”
(c) “All other cases ... are being placed on a waiting list...”
(d) “In the event that the court is of the view that a case should be considered as most urgent ... the court should kindly inform the ... Official Solicitor’s CoP Healthcare and Welfare teams...”
(e) “If at any time another litigation friend is appointed in this case before the Official Solicitor is in a position to accept the invitation the parties are asked to notify him as soon as possible, so that the file may be closed and the case removed from the waiting list.”

5. On 25 February 2013, the Official Solicitor issued a revised Note (here) on accepting invitations to act as litigation friend which stated:

(a) “I will continue to accept as a priority serious medical treatment cases. I will continue to be willing to consider giving priority to any other case on its particular facts, if a proper case is made out for expedition.”

(b) Once the criteria for the Official Solicitor acting are met, “cases are still likely to have to be placed on the waiting list to be accepted in chronological order once a case manager becomes available.”

(c) “I only act in the last resort. Enquiries should be made of possible alternative litigation friends and if a suitable and willing person can be identified, I will not normally act; if the court considers that any proposed alternative litigation friend is unsuitable for any reason, that should be made clear when I am asked to act.”

6. These statements have meant that IMCAs are now seeing an increase in being asked to be a litigation friend for their client. For example, local authorities progressing cases to the...
Court of Protection are exploring whether IMCAs may undertake the role. IMCAs themselves are approaching solicitors to discuss their potential appointment as litigation friend in cases where they feel the Court should be approached.

**IMCAs as Litigation Friends? Legislation and Guidance**

7. Section 36 of the MCA provides for regulations to determine the functions of an IMCA. According to Regulation 6 of the Mental Capacity Act 2005 (Independent Mental Capacity Advocates) (General) Regulations (SI 2006/1832), the functions include the following:

(a) “The IMCA must determine in all the circumstances how best to represent and support P”;

(b) “The IMCA must evaluate all the information he has obtained for the purpose of (a) ascertaining the extent of the support provided to P to enable him to participate in making any decision about the matter in relation to which the IMCA has been instructed…. (c) ascertaining what alternative courses of action are available in relation to P”.

8. How best to represent P may be through Court of Protection proceedings. Moreover, the relevant decision may include that of the Court under MCA section 16 and a course of action alternative to, for example, an informal best interests decision may be to take legal proceedings.

9. Regulation 7(2) goes on to state, “The IMCA has the same rights to challenge the decision as he would have if he were a person (other than an IMCA) engaged in caring for P or interested in his welfare”. One way of challenging the decision is through Court proceedings.

10. While the MCA Code of Practice does not refer to an IMCA bringing proceedings as P’s litigation friend, the Code does envisage IMCAs bringing matters to the attention of the Court:

• Para 10.37 MCA Code of Practice:
  “In particularly serious or urgent cases, an IMCA may seek permission to refer a case to the Court of Protection for a decision. The Court will make a decision in the best interests of the person who lacks capacity.”

• Para 10.38 MCA Code of Practice:
  “The first step in making a formal challenge is to approach the Official Solicitor (OS) with the facts of the case. The OS can decide to apply to the court as a litigation friend (acting on behalf of the person the IMCA is representing). If the OS decides not to apply himself, the IMCA can ask for permission to apply to the Court of Protection. The OS can still be asked to act as a litigation friend for the person who lacks capacity.”

**IMCAs as Litigation Friends? Concerns**

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
11. We have anecdotal evidence of IMCAs accepting invitations from the Court of Protection to undertake the litigation friend role in both DoLS and non-DoLS cases. In relation to the former, in AB v LCC (A Local Authority) [2011] EWHC 3151 (COP) Mostyn J. gave guidance regarding the circumstances in which a Relevant Person’s Representative (which is often an IMCA) can act as litigation friend.

12. Our series of seminars have highlighted the following matters:

- IMCAs have never received any specific training on the role of litigation friend;
- IMCAs have not received any specific guidance on the expectations of the role; this includes going to Court and how this works;
- Commissioners do not necessarily factor in this element of the role with respect to funding and are therefore unaware of what the role entails including the amount of time a Court case may require.

13. We would be grateful if the Select Committee could specifically address the following concerns:

- Local authority commissioning of IMCA contracts does not promote independence.
- The funding provided for IMCA services does not reflect the increased demand for IMCAs carrying out the role of litigation friend.
- IMCAs may also need to check with their organisation that their insurance covers them to carry out this work, if it doesn’t IMCAs will need to consider getting their own insurance which carries a personal financial cost that they may not be able to cover.
- In usual circumstances where an IMCA service sees a demand in the increase of instructions, such as serious medical treatment or accommodation decisions (or DoLS), they should be able to approach commissioners with an outline of the demand and therefore the rationale for requiring further funding. However where this demand increases due to carrying out the role of litigation friend, IMCA providers are effectively approaching commissioners for more funding to take them to court. Of course this is a simplistic way of looking at the issue but is a very real concern from providers and as such means that some IMCA services are choosing to not carry out the role or are more selective in when they can be due to limited resources.
- This in turn has led to some providers agreeing in their commissioned contracts that they will not carry out this role which appears to conflict with Regulation 7 above.
- If an IMCA is expected to challenge decisions where it is deemed necessary and appropriate, and an element of this challenge may involve progressing a case to the Court of Protection, then a contract that states IMCAs will not carry out the role of litigation friend appears to contradict the Regulations. This raises the question as to when the element of challenge stops. This in turn would appear to leave P without a voice and to go against the core elements and principles of the Act.
- To add to this, whilst there is an expectation that IMCAs would challenge the decision, many providers feel pressure from their commissioners to not fulfil this role. Many IMCA providers have told us that commissioners imply their contract will not be renewed or that it will be reviewed if they pursue going to court. Reasons given are the level of cost against local authorities when a case goes to court. One could argue they would face these
costs anyway if a family member progressed the case but the reality is family members are not commissioned and funded by the local authority, IMCA services are.

- Some IMCAs are therefore reluctant to bite the hand that feeds them which contradicts the essence of an IMCA.

14. One way to resolve some of these issues would be for IMCA services to be commissioned through a different funding stream which envisages their role as encompassing that of a litigation friend. With the benefit of training, we consider that IMCAs can fairly and competently conduct proceedings on behalf of P with no adverse interests so as to satisfy COPR r.140(1). Of course their legal costs will need to be protected in the same way as that of the Official Solicitor.

Signed: Jakki Cowley & Sue Lee
Directors

Dated: 29/08/2013

**Case study** – the following is taken from a solicitor’s website as an example of the benefit of IMCAs being a litigation friend.

The solicitor’s public law team was instructed by an Independent Mental Capacity Advocate ("IMCA") to act for L, who was aged 54 and had a diagnosis of Schizophrenia. L was a patient in a psychiatric ward at her local hospital, having been originally admitted under section 3 of the Mental Health Act 1983.

As a result her section was lifted, but she was not discharged to her home because it was felt that she would be at risk of exploitation by her son and daughter, who lived at L’s residence. In the past L had been physically, emotionally and financially abused by her son and daughter. L repeatedly expressed her desire to return home, and her IMCA spoke with the local authority social services department in an attempt to break the deadlock.

The local authority considered making an application to the Court of Protection, but in the end declined to do so and so L’s IMCA sought legal advice from a solicitor on L’s behalf. Legal Aid was obtained in L’s name, based on a means test of L’s finances, and a formal letter was sent to the local authority requesting that they apply to the Court of Protection seeking orders to remove the son and daughter from the home in order to allow L to be discharged from hospital.

The solicitors’ public law team applied to the Court in L’s name, with L’s IMCA instructing the solicitors on L’s behalf in a formal legal role known as ‘litigation friend’. The matter came before a Judge of the Court of Protection, who made orders for an expert’s report to be received on the issue of L’s mental capacity. The expert’s report confirmed that L lacked the capacity to make decisions about her own welfare and therefore the Court was able to make orders requiring the son and daughter to leave the property, allowing L to return home. The Court also made orders to not allow the son and daughter to have contact with L except under the supervision of the local authority.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
During the course of the proceedings, the Court approved of the appointment of L’s IMCA to act as her litigation friend in these proceedings, which came about solely as a result of the steps taken by the IMCA to seek legal advice on behalf of L.

2 September 2013
The Essex Autonomy Project – Written evidence

Summary: In this submission to the House of Lords Committee on the Mental Capacity Act, Professor Wayne Martin of the Essex Autonomy Project addresses Question 27 in the Committee’s Call for Evidence: Is the MCA compliant with the United Nations Convention on the Rights of Persons with Disability? A vocal group of critics has argued that the best interests provisions of the MCA stand in violation of the UNCRPD. But the arguments advanced in support of this position are fallacious. Given a reasonable interpretation of Art. 12 of the Convention, the best interests provisions of the MCA are indeed compliant with its requirements.

1. I write in response to the Committee’s Call for Evidence in connection with its post-legislative scrutiny of The Mental Capacity Act (MCA). My name is Wayne Martin; I am Professor of Philosophy at the University of Essex. I am writing in my capacity as Principal Investigator of The Essex Autonomy Project (EAP). The EAP is a research and knowledge-exchange initiative that has been investigating the ideal of self-determination in the so-called vocations of care (health care, eldercare, social care, psychiatric care, etc.). The work of the EAP has been funded by major grants from the Arts and Humanities Research Council, the British Academy, and the Wellcome Trust, and we have done extensive collaborative public policy work with, inter alia, the Office of the Public Guardian, the NHS, Amnesty Ireland, the Royal College of Psychiatry, and the Court of Protection. We regularly run workshops and training sessions on the MCA with researchers, jurists, and frontline care professionals. Further information about the EAP is available on the project website.

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31 http://autonomy.essex.ac.uk

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interest assessor) is said to “substitute” his or her judgement for that of the incapacitated individual.

2. The Mental Capacity Act does not in fact define the concept of “best interests;” instead it stipulates a procedure that should be followed in order determine a patient’s best interest in particular cases. This procedure is more fully elaborated in the MCA Code of Practice and in landmark rulings of the Court of Protection. That procedure is now used on a daily basis in clinical settings, in emergency services, in social care, in hospices, by the police, in psychiatric hospitals . . . . In a tiny proportion of cases the courts are called upon to resolve difficult cases and disputes. But critics have alleged that the very principle of best interests decision-making, and hence the fundamental architecture of the MCA, constitutes a violation of the human rights framework established by the UNCRPD.

3. To get a flavour of the criticism, it helps to start with a quick review of recent developments in the Republic of Ireland. When the current Irish coalition government came to power in 2011, one plank of its coalition agreement was a pledge to bring Irish mental health legislation into line with the UNCRPD. The first steps toward fulfilling this promise came later that year with the publication of a “scheme” for a planned new Mental Capacity Bill for the Republic of Ireland. The published scheme closely followed in the grooves established by the MCA, distinguishing between patients with and without mental capacity, and providing for best interests decision-making where capacity was lacking.

7. Early in 2012, a joint committee of the Irish Parliament held hearings on the published scheme. A number of organisations made submissions to the Joint Committee arguing against the inclusion of the proposed best interests framework. Indeed the drumbeat of criticism was so insistent that that chairman of the Committee, in his report on the hearings, wrote that “Concerns were raised by the use of the best interests model. It was stated to the Committee that this is a model of the past.” The nub of the critics’ argument can be found in this passage from a representative submission from the Centre for Disability Rights, NUI Galway:

The Need to Radically Re-Frame “Best Interests” to pivot on the “Will and Preferences” of the Person: The Scheme of the Bill does make reference to the wishes of a person that may have been expressed previously and indeed presently. However, there is no provision to have these wishes enforced legally in future circumstances where they are deemed to lack capacity. The best interests principle emerged from law and policy focused on children and it is increasingly considered inappropriate in relation to adults. As stated a central aspect of Article 12 is the focus on the “will and preferences” of the person as the determining factor in decisions about their life and this requires moving away from a “best interests” approach, which brings with it the significant risk of paternalism. This requires a significant change in thinking and needs to be embedded in the Bill.


54 Centre for Disability Law & Policy NUI Galway, “Submission on Legal Capacity to the Oireachtas Committee on Justice, Defence & Equality”; In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
8. The criticisms have, at this point, been effective in Ireland. When a draft bill was finally introduced into the Oireachtas earlier this summer, it wholly dispensed with the best-interest approach that animates the MCA. Even the title of the bill has changed: it is no longer known as “The Mental Capacity Bill”, but as “The Assisted Decision-Making (Capacity) Bill 2013”.

9. So why exactly should best interests decision-making be consigned to the dustbin of history? We can distinguish two distinct lines of argument in the NUI submission. One argument concerns the origins of the best interest standard and the allegation of an objectionable paternalism in its application to adults. The second argument pertains specifically to the provisions of Article 12 of the UNCRPD. Article 12 of the Convention concerns equal protection under the law for persons suffering from disabilities. The argument here is that its focus on the will and preferences of the person is ultimately inconsistent with the best interests framework.

10. In the best interests decision procedure prescribed by the MCA, the will and preference of the patient are always matters to be taken into account – at least insofar as it is reasonable and practicable to do so. A patient with dementia being discharged from hospital may be found to lack capacity regarding decisions as to her place of residence. But if it is known that she has a strong preference to return home to live with her partner, then the best interests assessment must take this into account, even if it is the judgement of the clinical team that discharge to a care home would be a safer alternative. A patient facing a high-risk surgical procedure may be found incapable of making his own decision about whether to proceed with the surgery due to a serious learning disability; nonetheless his own desire to proceed with the surgery must be taken into account in an assessment of his best interests. Of course there are many emergency situations in which there is simply no time to determine the preferences of the patient: think of the situation of a paramedic at the roadside or a clinical team dealing with an unaccompanied unconscious patient at A&E. But where it is reasonable and practicable to do so, the statute, the Code of Practice and the rulings of the Court of Protection are clear: the preferences of the patient are always relevant to a determination of best interest.

11. But that does not mean that the will and preference of the patient is always decisive in a best interests judgement under the MCA. The MCA operates with what is known in law as an “objective best interests standard.” The best interest assessor is called upon to use his or her own judgement in making an objective determination as to the patient’s overall best interest. The patient’s will and preference is one factor to be taken into account in such a determination, but it can be outweighed by other factors. Consider an extreme example: Suppose that I am a heroine addict, recently admitted to hospital after an overdose. My immediate medical condition has been stabilised but I am still in a highly


56 Re M; ITW v Z [2009] EWHC 2525 (Fam), §35.

57 Re P [2009] EWHC 163 (Ch), §37.

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agitated and distressed state. My decision-making capacity is compromised both by the medical consequences of the overdose and by the compulsions associated with addiction. The medical team finds that I presently lack mental capacity to make a decision about continuing care and support after discharge. A best interests meeting is convened. In such a circumstance, my own will and preference might be to adopt the care plan that will make it easiest for me to get my next fix. Under the MCA, an assessment of my best interests will need to take that preference into account. But it need not be the decisive factor in the determination of my overall best interests. Accordingly, the best interest judgement might in such a circumstance override my will and preference in order to act in my objective best interest.

12. This feature of the MCA best interests decision procedure can result in highly intrusive and coercive interventions. The courts have in recent years ordered, inter alia, that adults be separated from their adoptive parents; that a person with a severe head injury must be kept alive despite clearly expressed preference to be allowed to die; and that a woman with very longstanding and severe anorexia nervosa be force fed for a period of one-to-two years, using whatever physical and/or pharmacological restraint as might be required to overcome her resistance. These cases are disturbing and controversial. The Irish disability rights community is not alone in holding that they constitute a violation of international human rights standards.

13. One particularly important voice in the chorus of critics comes from the UN itself. The UNCRPD established a new body within the United Nations: the Committee on the Rights of Persons with Disabilities. Among its several responsibilities, this UN Committee issues country reports which formally assess compliance with the provision of the Convention. To date there has been no report on the UK, but an excerpt from the report on Spain exemplifies a claim that has appeared in many of the country reports issued to date.

The Committee recommends that the State party ... take action to develop laws and policies to replace regimes of substitute decision-making by supported decision-making, which respects the person’s autonomy, will and preferences. It further recommends that training be provided on this issue for all relevant public officials and other stakeholders.

Although the terminology here is different (the Committee speaks the language of “substituted decision-making” rather than “best interests decision making”), the position is clear: according to the international body charged with interpreting and applying the UNCRPD, states parties should be revising domestic legislation in order to eliminate provisions which allow a patient’s will and preference to be overridden on the basis of a substituted judgement. If this is indeed correct then the MCA will have to be fundamentally revised or abandoned in order to achieve UNCRPD compliance.

58 The PCT v P, AH and a Local Authority[2009] EW Misc 10 (EWCOP); Re M [2011] EWHC 2443 (Fam); Re E [2012] EWHC 1639 (COP).

59 The PCT v P, AH and a Local Authority[2009] EW Misc 10 (EWCOP); Re M [2011] EWHC 2443 (Fam); Re E [2012] EWHC 1639 (COP).

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14. So what does the Committee envision as an alternative to ‘best interests’ or ‘substituted’ decision-making? We can see their answer in this excerpt from the report on Spain. Regimes of substituted decision-making should be replaced by a framework of supported decision-making. This itself is a concept that figures prominently in the UNCRPD, notably in article 12, §3: “States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity” (emphasis added). Here we can see traces of a third line of argument that has been used to defend the negative position on Question 27: The UNCRPD calls for a framework of supported decision-making, whereby patients and disabled persons are provided with support to make their own decisions. But the MCA warrants a framework of substituted decision-making, whereby a best interest assessor is empowered to make a decision on behalf of a patient or disabled person. Therefore the MCA is not compliant with the UNCRPD.

15. We have reviewed three lines of argument intended to demonstrate that the MCA is not compliant with the UNCRPD. All three arguments are fallacious. The first argument is a textbook example of the genetic fallacy. The best interest decision-making framework may well have its legal origins in the law governing the care of children. But does this mean that it is always inapplicable to adults? The hot-button language of “paternalism” is really just a distraction here. It is of course true that parents sometimes override a child’s insistently expressed preferences on the basis of a reasoned judgement as to the child’s best interest. Perhaps they establish limits on the number of helpings of ice cream at dinner. The bioethical question is whether, for example, a medical team might do the same with an adult who suffers from both diabetes and Alzheimer’s. Let’s allow that such an intervention might be described as medical paternalism, and that it involves application of a jurisprudential framework that was originally developed for children. We are still left with the question of whether the intervention is ethically and legally justified.

16. The second line of argument is the one that should most concern us. The United Kingdom is a signatory to the UNCRPD, both in its own right and as an EU member state. It is therefore committed to reform its domestic law as necessary in order to achieve compliance with the Convention. The second line of argument purports to establish that the Convention precludes best interests decision-making. The fact that this argument has been advanced both by the disability rights community and by the relevant UN Committee should certainly give us pause. But let’s consider the logic of the argument more closely.

17. The legal basis for the argument rests on Article 12, §4 of the UNCRPD. It reads as follows:

States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person’s circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person’s rights and interests.

The critics’ argument can then be boiled down to two premises and a conclusion.
Premise 1: The MCA regime of substituted or best interests decision-making leaves room for the possibility of overriding the will and preference of the care-recipient.
Premise 2: UNCRPD Article 12 explicitly requires respect for the rights, will and preferences of the care-recipient.

Conclusion: The MCA regime of substituted best interests decision-making is not compliant with the UNCRPD.

The two premises are true, but the conclusion does not follow.

18. In assessing the argument, everything ultimately comes to turn on the word “respect.” What the UNCRPD requires is respect for the will and preferences of the patient. But what exactly does respect require? In order for the critics’ argument to be valid, the requirement to respect the patient’s will and preferences would have to mean that we must never override the patient’s will and preferences; we must always be bound by them. But is that really what “respect” means?

19. Let’s look first to the dictionaries. In OED, the first non-archaic definition of “respect” as a verb is “to regard, consider, take into account.” Webster’s Tenth Collegiate Dictionary defines “to respect” as “to consider worthy of high regard.” The definition in the Oxford Dictionary of English is also revealing: “to have due regard for.” On any one of this trio of definitions, a requirement of respect falls short of a requirement of absolute deference or non-interference. In particular, these definitions leave room for the possibility that I might respect the will and preferences of a patient (I take them into account, hold them in esteem, give them due regard) while nonetheless overriding them in the patient’s best interest. Moreover, given this understanding of “respect,” it is fair to say that the MCA best interest decision procedure itself requires respect. As we have seen, the MCA requires that the patient’s preferences be taken into account and given due regard.

20. But the matter cannot be settled quite so easily. For there are some dictionary definitions of “respect” that would establish a more rigid constraint. Definition 4c in OED is “to refrain from interfering with.” The same meaning is given as the second definition in Webster’s. The last definition in the Oxford Dictionary of English is “to agree to recognise and abide by.” If we adopt these definitions, then the critics’ second argument would go through. In requiring respect for the will and preferences of the patient, the UNCRPD would be requiring that we refrain from interfering with the exercise of the patient’s will.

21. In order to choose between these two meanings, the best strategy is to look at the meaning of “respect” in the distinctive discourse of international human rights law. A full survey of usage would be out of place here; two prominent and pertinent examples will suffice.

22. Consider first the European Convention on Human Rights. The word “respect” figures crucially in Article 8 of the ECHR, which concerns the right to respect for private and family life. Article 8.1 states the basic principle: “Everyone has the right to respect for his private and family life, his home and his correspondence.” But notice that Article 8.2 immediately goes on to enumerate a series of exceptions, which are specifically identified as circumstances in which the state is permitted to interfere with the exercise of this right.

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1. There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.

So the logic of ECHR Article 8 is clear on this point: respect for private and family life is compatible with some duly regulated interference in private and family life. If “respect” were interpreted to mean “never interfere with” then ECHR Article 8 would be flatly incoherent.

23. This pattern of usage is not a quirk of ECHR Article 8; it is ubiquitous in the language of human rights. For example, Article 11.2 of the European Union’s Charter of Fundamental Rights stipulates that “The freedom and pluralism of the media shall be respected.” If respect meant “never interfere with” then no regulation of press freedom would ever be permitted. So the critics’ second argument fails. Given any reasonable interpretation of the requirement of respect for the will and preferences of the patient, Article 12 of the UNCRPD is compatible in principle with a framework of substituted or best interests decision making.60

24. The third and final argument we canvassed turned on the contrast between a regime of supported decision making and a regime of substituted decision making. Since the UNCRPD operates with a paradigm of supported decision making and the MCA operates with a paradigm of substituted judgement, statues like the MCA need to be replaced with a new statutory framework. Or so the argument goes. But this third argument turns on a false disjunction; it presupposes that the contrast between a regime of support and a regime of substitution is somehow exclusive. It is not. The MCA is itself an example of legislation that adopts a combination of both frameworks. As we have seen, the best-interest framework of the MCA prescribes a procedure for the exercise of substituted judgement. But the MCA also incorporates the principle of support. Article 1.3 explicitly states: “A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.” So the Act insists that support be provided to patients to enable them to make their own decisions wherever possible. But it also recognises that patients are sometimes unable to make their own decisions. Under those circumstance it insists that the patient’s will and preference be respected (i.e., given due regard). But it does not dictate a blanket deference to the will and preference of the incapacitated patient; it requires the best interest assessor to exercise her own judgement as the to best interests of the patient, and it allows that this will sometimes require that the patient’s own preferences may be outweighed by other considerations as to his overall best interest. In this sense the Act is a hybrid -- a principled compromise that effects a strategic combination of the two frameworks between which the critics wrongly insist that we choose.

25. So the chorus of critics is mistaken, as least when it comes to this particular point of law and medical ethics. The MCA may or may not be fully compliant with the provisions of the UNCRPD; a host of further issues will need to be investigated by the

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60 I am grateful to Jason Coppel QC for his observations about the meaning of “respect” in international human rights contexts.

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Select Committee before a definitive answer can be given to the 27th Question. But the arguments advanced by the critics fail to show that compliance with the UNCRPD would require that the best interests framework of the MCA be abandoned.

2 September 2013
Executive Committee of the Eating Disorders Section of the Royal College of Psychiatrists (EDSECT) – Written evidence

We write on behalf of the Executive Committee of the Eating Disorders Section of the Royal College of Psychiatrists (EDSECT), in response to the Call for Evidence recently published by the House of Lords Select Committee on the Mental Capacity Act 2005. We welcome this opportunity to provide input into the review of this important piece of legislation.

The preparation of this submission was undertaken by Dr Nikola Kern and Dr Frances Connan. The recommendations contained herein are informed by a daylong seminar of the Eating Disorders Section, held on 23 April, 2013, which addressed the application of the MCA in the context of eating disorders.

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Chair of EDSECT and Chair of Eating Disorder Research, St George's University of London

1.0 **Background:** In this document we report on the application of the Mental Capacity Act (MCA) to challenges associated with eating disorders, and offer seven recommendations for improving the application of the MCA to this patient population.

1.1 Eating disorders are unusual among medical disorders in that the condition itself is one that is often valued by the sufferer. Ambivalence about treatment is therefore characteristic. For many patients, the positive experiences of the disorder outweigh negative consequences, despite high morbidity and high risk of death from starvation. Resistance to change and to treatment is therefore often strong.

1.2 Most health professionals see only a few cases of serious eating disorders, and have little understanding of the complex psychopathology. Stigma is high, with public and health professionals frequently conceptualising the disorders as self-inflicted ‘life choices.’ Experts are clear that an eating disorder is not a life choice – the psychopathology is characterised by powerfully motivated food-avoidance and abnormal beliefs about food and weight. This is often accompanied by impairment of insight, with minimisation of the seriousness of the risks. People with eating disorders are typically articulate and able to intellectually understand information about health risks. However, they frequently do not believe that they are at risk. There is a mismatch between their intellectual understanding, and their experience of feeling fine and not wanting to eat. People with eating disorders can therefore

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appear capacitous to those not experienced in their care; experts able to elicit the underlying psychopathology, and its impact on decision-making, frequently find a lack of capacity for decisions about food and other treatments.

1.3 Refusal of nutrition and treatment is common in eating disorders, and often becomes more insistent as the disorder progresses. These refusals present legal, clinical and ethical dilemmas for practitioners and family members. Should we honour the refusal and refrain from treatment? Or should we override the refusal in order to administer what may be life-extending treatment? The MCA now sits alongside the Mental Health Act in providing legal guidance in navigating these dilemmas, and provides a structured framework for assessing both capacity and best interests. All this is to be welcomed. Nonetheless there are several areas in which there is need for clarification and guidance in the application of the Act in the context of eating disorders. There are also areas in which the challenges involved in treatment for eating disorders have exposed fundamental stresses within the Act itself.

2.0 MCA Definitions of “Capacity” and “Best Interests”: Question 3 in the Call for Evidence asks whether the MCA definitions of “capacity” and “best interests” are appropriate. On the whole we believe they are appropriate. However on two matters we find that the definition of “capacity” presents difficulties in the context of eating disorders.

2.1 The first matter pertains to issue as to whether the patient believes or appreciates the information that is provided concerning diagnosis and risk. In US jurisdictions, the definition of competence characteristically includes a requirement of appreciation in addition to understanding.\(^{61}\) In pre-MCA case law, the so-called “Eastman Test” included a requirement of believing information in addition to understanding it.\(^{62}\) But the MCA definition omits any mention of belief. This could be seen as a superficial difference in wording, or it could be understood as a deeper difference in approach. In the assessment of capacity in eating disorders, this makes a difference. A patient with an eating disorder may well understand information that is provided to her concerning the risks of low body weight. She can readily paraphrase it in her own words, for example. But patients with eating disorders often have trouble believing that the information provided really applies to them. They are often convinced that they will “beat the odds.” In extreme cases this conviction can be of delusional intensity. In our patient population, the inability to believe information can compromise a patient’s ability to incorporate medical advice into the decision process.

2.2 The second feature of the MCA definition of “capacity” that concerns us is its apparently exclusive focus on the deliberative process rather than the process of actually putting a decision into effect. Some of our patients are able to understand, retain, use and weigh information, and communicate a choice. But they then find themselves unable to implement that choice, so no action results. The disorder is characterised by profound ambivalence about recovery. The need to manage others through placation is a common

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62 Re C (An Adult: Refusal of Treatment) [1994] 2 FCR 151: “[T]here are three stages to the decision: (1) to take in and retain treatment information, (2) to believe it, and (3) to weigh that information, balancing risks and needs.”

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feature. Taken together, these features may result in patients placating clinicians with verbal expressions of intention to change, whilst the more powerful drive to resist change is unspoken, and expressed through lack of action toward change/treatment goals.

2.3 Recommendation One: There should be scope within the MCA definitions to reach a finding of incapacity where a patient exhibits a systematic inability to believe information relevant to their disorder, or an inability to translate deliberative outcomes into action.

3.0 The Slippery Slope Towards an Outcome or Status Test: Question 4 in the Committee’s Call for Evidence asks to what extent the five principles of the MCA have been implemented in frontline practice. We have encountered challenges in implementing the principle expressed in MCA §1.4: “A person is not to be treated as unable to make a decision merely because he makes an unwise decision.”

3.1 The Law Commission’s 1995 report on Mental Incapacity distinguished three approaches to the definition and assessment of mental capacity: a status test, an outcome test, and a functional test.63 One respect in which the MCA has been seen as a progressive piece of legislation is in its adoption of the functional test rather than either a status or outcome test for capacity. One’s autonomy rights should not be decided on the basis of one’s mental health diagnosis; it should be predicated on what one can actually do. Accordingly, the legal test for mental capacity turns on the abilities specified in MCA §3.

3.2 We welcome this approach, but we must also recognise the extent to which it is put under pressure by the exceptional challenges associated with severe eating disorders. In cases of severe and enduring anorexia nervosa, in particular, a patient may refuse food all the way to the point of permanent organ damage or even death. Such a choice can be extremely difficult for others to understand, and it can be all-too-easy to conclude that such a decision ipso facto demonstrates a lack of capacity. We must recognise that there is, in this area of practice, an intrinsic tendency to apply an outcome test for capacity.

3.3 It is also important to recognise a tendency in law that can push us towards a status test in the context of eating disorders. In the MCA Code of Practice, the person with anorexia’s compulsion not to eat is provided as one of two examples of the inability to use or weigh information as part of the decision-making process.64 The courts have on several occasions invoked the compulsive fear of weight-gain as the decisive obstacle to capacity in decisions about food and treatment.65 As this line of clinical assessment and legal reasoning has become established, there is a danger that a diagnosis of severe AN can itself become tantamount to a finding of incapacity for decisions regarding eating and treatment.

3.4 This tendency towards a status test can be seen in recent cases where capacity has been adjudicated in the courts. One court-appointed expert in a recent Court of Protection

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63 Law Commission Report No 231, Mental Incapacity (London: HMSO, 1995); §3.3.

64 Mental Capacity Act 2005 Code of Practice (London: TSO, 2007); §4.22.

65 A Local Authority and E[2012] EW7HC 1639 (COP), §49. The NHS Trust and L[2012] EW7HC 2741 (COP), §53. See also the important pre-MCA case, re W (a minor) (medical treatment) [1992] 4 All ER 627.

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case expressed the view that anyone with severe anorexia lacks capacity to make decisions about food and treatment. If such a view is correct then the functional test for capacity collapses, in the case of severe eating disorders, into a status test. But while dread of weight gain is one of the diagnostic criteria for anorexia nervosa, the intensity of dread varies, and must be assessed in every case, and at every point of significant decision making, to establish whether it impairs the capacity to weigh information in the balance in respect of a particular decision.

3.5 Recommendations: The slippery slope towards an outcome test or status test should be managed by ensuring that the capacity assessment is informed both by an understanding of the disorder and by an understanding of individual circumstances and mental state of the particular patient. Since specialists cannot be available at all times in all treatment contexts, a multi-pronged approach is needed.

3.6 Firstly, further guidance on eating disorders should be included in the Code of Practice in order to improve quality of capacity assessments in general health care settings. Such guidance should include warnings to be aware of the risk of collapsing the test into an outcome or status test and emphasis on the need to document specific evidence of lack of capacity in each individual with respect to each specific decision.

3.6 Secondly, where decisions with serious consequences are to be made, an expert should be sought at the earliest available opportunity.

3.7 Thirdly, where decisions are to be made in the Court of Protection, experts approved by the Royal College of Psychiatrists Eating Disorder Section should be appointed to provide independent opinions. Where judges are called upon to adjudicate capacity, every effort should be made to facilitate direct contact with the patient.

4.0 The Presumption of Capacity: Also in connection with Question 4 in the Call for Evidence, we wish to draw attention to difficulties that have arisen in applying the principle expressed in MCA §1.2: “A person must be assumed to have capacity unless it is established that he lacks capacity.” This principle of presumption is a fundamental commitment of the Act, and we endorse it. Nonetheless we find that it is often misunderstood by practitioners, sometimes with quite negative consequences for care.

4.1 The crucial background on this point is that some patients with eating disorders are extremely “high functioning” – intelligent and articulate, and sometimes also quite knowledgeable about medical and legal matters. Published research has shown that at least some patients with eating disorders score highly on standardized tests for competence. We have often seen cases where capacity assessors are “taken in” by superficial traits and hence fail to uncover the underlying incapacity. One circumstance that we have encountered

66A Local Authority and E[2012] EWHC 1639 (COP), §52-53.


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involves a situation where a consultant with specialist training finds a patient to lack capacity, and an in-patient treatment plan is agreed in the patient’s best interest. But over the weekend or after hours, a junior doctor with less specialist training or experience may be confronted by the same patient insistently demanding to return home against medical advice. In such circumstances, the junior doctor may lack the experience and expert knowledge to elicit the evidence of lack of capacity. Given the principle of presumption of capacity, and the recognition that capacity itself can fluctuate, the doctor may feel that s/he has no choice but to allow an intelligent and articulate patient to refuse care.

4.2 **Recommendation Three**: Guidance and training is required in order to ensure that practitioners understand the legal notion of presumption. The legal presumption of capacity should be understood to be compatible with the exercise of a significant degree of scepticism in the conduct of a capacity assessment for patients suffering from severe eating disorders. There is a subtle balance to be struck here. A finding of incapacity must be based on evidence sufficient to overturn the presumption; but the discovery of such evidence may indeed require an investigation that is animated by a suspicion that the patient lacks capacity to make decisions about treatment.

5.0 **The MCA and the MHA**: Question 8 in the Committee’s Call for Evidence asks whether the MCA has ushered in the expected, or any, change in the culture of care. In our experience, the impact on the culture of care has varied across institutional settings. Nonetheless many of our practitioners have found that the MCA has changed the culture of care by introducing a second legal instrument that sits alongside the Mental Health Act.

5.1 Prior to the introduction of the MCA, the primary instrument for involuntary treatment of persons with a eating disorder was the Mental Health Act (MHA). An MHA section provides the legal authority to provide care, even over objections from the patient. MHA sections are still used in providing involuntary treatment for patients with eating disorders. But the Mental Capacity Act has now provided an additional tool in the legal toolbox.

5.2 In some settings of care, the MCA and MHA are viewed as providing the possibility for a graduated series of interventions. A patient who is refusing both food and treatment may in the first instance be assessed for capacity under the MCA. If capacity is found to be lacking (as it very commonly is), this is itself explained to the patient, and a treatment plan is decided, with the patient’s involvement, in her best interests. Often this is sufficient to move forward with therapeutic interventions. It is only if the patient then resists the prescribed treatment that the next step is made: consideration of a Mental Health section.

5.3 The advantage of the MCA over previous common law covering incapacitous patients is that it has embedded more firmly the notion of capacity as central to the decision making process. We believe that this change in practice has been constructive. The patients in our care are often very sensitive to formal legal designations that are applied to them; the availability of an additional set of tools that fall short of the MHA section can sometimes improve the therapeutic relationship. A finding of incapacity can also serve to emphasise to the patient that what the team seeks is recovery of decision-making capacity (i.e., autonomy), rather than simply weight-gain.

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5.4 Nonetheless, this interface between the MHA and the MCA has also raised difficulties in practice, and has sometimes been the occasion of confusion and controversy. The MHA and the MCA have overlapping jurisdiction, and many of our patients can in principle be treated under either legal regime. We have sometimes heard it argued that the MHA “trumps” the MCA, and one judgement of the Court of Protection has raised concerns about whether it is acceptable to “pick and choose” between the statutes. In our experience, the guidance offered under MCA§28 has not been sufficient to resolve these disputes; in practice, clinicians are in fact making pragmatic clinical judgments as to which of the two statutes to apply in particular cases.

5.5 **Recommendation Four**: The interface between the MHA and the MCA should be clarified.

6.0 **The Entanglement of the Capacity Judgement and the Best Interests Judgement**: Further to Question 8 in the Call for Evidence, there is one respect in which we believe that the Act has not resulted in the intended change of culture. The basic architecture of the MCA is predicated on the supposition that one can sharply distinguish between the assessment of mental capacity and the exercise of a best interest judgement. Part of the change of culture called for under the Act, as we understand it, is that doctors and other medical practitioners will “check” their paternalistic instincts in order to assess capacity prior to acting in the best interests of the patient. But in practice the two stages distinguished under the Act cannot be so neatly disentangled. A practitioner dealing with an eating disorder patient may face a very difficult judgement as to the presence or absence of mental capacity. Both the process of assessment and its outcome are in effect clinical interventions in the life of a highly vulnerable patient, who may herself be highly sensitive to the granting or withholding of this form of recognition. Clinical practitioners inevitably have these impacts on the patient in mind in addressing the question of capacity. Accordingly the outcome of the capacity assessment is in practice informed by a judgement as to best interest. This dilemma is very likely unavoidable; we simply need to learn to live with it, while at the same time guarding against adopting an unfettered pragmatism in applying the law.

6.1 **Recommendation Five**: It should be recognised that the law in this area is to a certain extent predicated on a set of fictions: the fiction of a sharp line separating those with and without capacity, and a sharp line separating the assessment of mental capacity from the determination of best interests.

7.0 **Best Interests and the Cessation of Treatment.** One of the most difficult set of questions in the care of persons with serious eating disorders concerns the initiation, continuation, and discontinuation of involuntary treatment. Involuntary treatment can take a variety of different forms, including involuntary residential care; compulsory monitoring of weight, exercise and caloric input; control over diet; and compulsory ways of feeding. Involuntary treatment can be highly coercive, in some cases involving physical and/or pharmacological restraint. In some cases the involuntary treatment can itself symbolically or literally re-enact forms of abuse to which patients had been subject as children. The best

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69GJ v The Foundation Trust (2009) EWHC 2972; §45.

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interests decision procedure in the MCA provides a useful framework for navigating these challenges, but it also has dangers and limitations.

7.1 One significant danger in a best interests assessment is the danger of getting trapped in false disjunctions. Although the best interests guidelines explicitly call for all options to be considered, it is all-too-easy for best interests assessments to fall into the trap of considering only the most extreme options (i.e., cessation of treatment or coercive force feeding). It is crucial to ensure that all treatment options are considered in determinations of best interests for persons with eating disorders.

7.2 Special challenges arise in connection with the question of discontinuation of treatment for life-threatening eating disorders. Two prominent 2012 Court of Protection cases have provided some guidance on this ethically fraught question, but there is a need for more detailed guidance. There is a need for reflection and research concerning the point at which continued coercive treatment becomes counter-productive, not simply in terms of medical futility, but in terms of the broader psychological and ethical consequences of involuntary medical intervention.

7.3 Recommendation Six: More detailed guidelines should be developed in consultation with the Eating Disorder Section of the Royal College of Psychiatrists concerning the application of the best interest standard in the context of eating disorders.

8.0 The Need for Specialist Training and Expert Testimony. We note with approval the recent announcement concerning the plan to provide specialist training to judges and barristers who work with certain highly vulnerable groups of witnesses. Although this announcement concerned criminal proceedings dealing with the sexual abuse of children, we believe that there is a need for an analogous programme of training for judges who deal with capacity assessments and best interests determination for patients with eating disorders – particularly in cases where highly coercive measures are proposed on the basis of a best interests assessment.

8.1 The role of court-appointed expert witnesses is an important part of judicial proceedings. We see a role for the Royal College in providing a list of qualified experts to serve in this capacity. Where highly coercive measures are proposed on the basis of a best interests assessment, we believe that a minimum of two court-appointed expert witnesses should provide testimony.

8.2 Recommendation Seven: Specialist training should be made available to Court of Protections judges who are called upon to assess the mental capacity and best interests of


71 A Local Authority and E[2012] EWHC 1639 (COP); The NHS Trust and L [2012] EWHC 2741 (COP).


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persons with eating disorders. Where highly coercive methods of treatment are proposed on the basis of a best interests assessment, at least two suitably qualified experts should be consulted, with a list of qualified experts provided to the court by the Royal College of Psychiatry.

2 September 2013
Introduction

1. This submission is written by Professor Phil Fennell and Dr Lucy Series. Phil Fennell is a professor of law at Cardiff University Law School. He has written many books and articles on mental health law. Most recently he co-authored with Professor Bartlett, Gostin, McHale, and Mackay Principles of Mental Health Law and Practice (2010) Oxford University Press, and with Penny Letts and Jonathan Wilson he wrote a guide to the operation of Mental Health Tribunals in England and Wales (Mental Health Tribunals, Law Society) which was published in April 2013. The second edition of his own book, Mental Health Law and Practice was published by Jordans in 2011. Phil served as specialist legal adviser to the Joint Parliamentary Scrutiny Committee on the Mental Health Bill 2004, and to the Joint Committee on Human Rights on the Mental Health Bill 2006, which became the Mental Health Act 2007. Dr Series recently finished her doctoral thesis on the Mental Capacity Act 2005 (MCA), part of which focused on access to justice under the MCA and the deprivation of liberty safeguards. In October, Professor Fennell and Dr Series, in conjunction with Professor Luke Clements and Dr Julie Doughty at Cardiff Law School will begin a piece of research into efficiency, transparency and accessibility in the Court of Protection in relation to health and personal welfare disputes. The research has been granted funding by the Nuffield Foundation.

2. Although there are a number of questions about the substantive principles of the Mental Capacity Act 2005 (MCA), especially in view of the UN Convention on the Rights of Persons with Disabilities (CRPD), this submission will focus on two key procedural matters: the deprivation of liberty safeguards and access to justice. Whilst the UN CRPD does contain provisions which are relevant to these procedural matters – especially Article 12 (equality before the law), Article 13 (access to justice) and Article 14 (liberty and security of the person) – this submission focuses particularly on the compliance of the MCA and the deprivation of liberty safeguards (DoLS) with the procedural guarantees of the European Convention on Human Rights (ECHR). We submit that the procedural safeguards on decisions made under the MCA, and available to people deprived of their liberty in connection with the DoLS, are not adequate to comply with the ECHR. Although only a relatively short time has elapsed since the time the MCA was drafted and passed into law, international human rights law in relation to legal capacity has moved on substantially, and it would be appropriate for the Committee to take a fresh look at these issues.

GENERAL JURISPRUDENCE ON ACCESS TO JUSTICE

3. People with mental disabilities often find themselves subject to the power of caregivers – private or public – in relation to all choices, rights and freedoms. The very purpose of the MCA was to provide some kinds of constraints and principles for the kinds of interferences with a person’s choices and freedoms which were acceptable on grounds of incapacity. Setting aside the question of whether or not those substantive principles were, or are, an appropriate choice – this goal is in accordance with the ideal of the rule of law. The ideals of the rule of law underpin the ECHR, and they are that law should be ‘adequately accessible’ and drafted with ‘sufficient precision’ to enable citizens to regulate their conduct accordingly (The Sunday Times v United Kingdom [1979] ECHR 1, § 49). We share the concerns of Mostyn J, expressed in J Council v GU & Ors (Rev 1) [2012] EWHC 3531 (COP),
that the principles of the MCA appear to permit wide ranging interventions which will affect a person’s liberty, privacy and rights to home and family life, with minimal guidance. In many situations, the absence of clear guidance may violate the principle of the rule of law and Article 8 ECHR.

4. The European Court has also found that one can ‘scarcely conceive of the rule of law without there being a possibility of having access to the courts’ (Golder v UK [1975] ECHR 1, §34). In short, if the MCA really is to protect against arbitrary interferences with a person’s legal rights, then an effective legal remedy for violations of those rights must be accessible to the person concerned. We submit that the MCA falls short of this goal.

5. In theory a remedy exists for any dispute or concern connected with a person’s mental capacity and best interests: an application to the Court of Protection. In practice, this evidence suggests that the remedy is not accessible to the very people who would need to rely upon it. The shortcomings of the deprivation of liberty safeguards to provide an accessible means to appeal against one’s detention, in accordance with Article 5(4) ECHR, are discussed below. But we draw to the Committee’s attention that effective access to a court may also be required by the MCA for a wide range of other matters relating to the MCA, as they will engage Article 8 ECHR.

6. At the time the MCA was drafted, there were comparatively few judgments relating to legal capacity and mental disabilities (see the foreword of Sir Nicolas Bratza in Bartlett, P., Lewis, O. & Thorold, O. (2007) Mental disability and the European Convention on Human Rights, Leiden, the Netherlands: Martinus Nijhoff Publishers). However, a large number of cases have now come before the European Court of Human Rights, where the judges have emphasised the importance under the ECHR of access to a court for matters relating to legal capacity.

7. In Shtukaturov v Russia [2008] ECHR 223 the Court asserted that deprivation of legal capacity is as important an issue under the ECHR as deprivation of liberty. Because of the informal nature of the MCA, ‘deprivation of legal capacity’ under the MCA does not occur in the same way as it does in jurisdictions where a person may only be treated as ‘lacking capacity’ once they have been so found by a court. In England and Wales, in relation to the vast majority of care and welfare decisions, a person may be treated as ‘lacking capacity’ where the person making a particular intervention reasonably believes that they ‘lack capacity’ and the course of action is in their best interests (s5-6 MCA). Although the informal approach and the decision specific nature of capacity are regarded as some of the Act’s main advantages, it does mean that there are very few procedural safeguards against such decisions. In practice, a person might find that they are ‘deprived of their legal capacity’ in a wide range of personal matters engaging their fundamental human rights without a court ever being involved. We submit that the informal and decision-specific nature of the MCA should not blind us to the reality that a person may lose a tremendous amount of autonomy in their life without any formal court declaration.

8. In recognising that deprivation of legal capacity could be of fundamental importance in relation to all other ECHR rights, the European Court has held in Stanev v Bulgaria [2012] ECHR 46, Kędzior v Poland [2012] ECHR 1809 and Makhaylenko v Ukraine [2013] ECHR 484 that Article 6 must be interpreted as ‘guaranteeing a person, in principle, direct access to a court to seek restoration of his or her legal capacity’ (Kedzior v Poland, §85). In D.D. v Lithuania [2012] ECHR 254 §118 the court also held that when a person is in conflict with

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their guardian (a third party decision maker for people deprived of legal capacity) and ‘when
the conflict potential has a major impact on the person’s legal situation’ it is essential that the
person concerned must have access to the court (see also MS v Croatia [2013] ECHR 378 §
80, 107). Although not a case concerning legal capacity, in X v Finland [2012] ECHR 1371
the European Court of Human Rights found that a person should have access to a judicial
review of any involuntary medical treatment which they object to. We submit that in
England and Wales, this should be interpreted as meaning that a person should enjoy
guaranteed access to a court to a) challenge any finding of incapacity which engages their
ECHR rights, or b) to bring any dispute with a ‘best interests’ decision maker, over a matter
which engages their ECHR rights, before a court.

9. There are no explicit statutory or regulatory bars against people who ‘lack mental
capacity’ making an application to the Court of Protection for this purpose. Indeed,
s50(1)(a) MCA explicitly states that a person who lacks or is alleged to lack capacity does
not need the permission of the Court of Protection to make an application under the MCA.
However, people who are said to lack capacity will face many practical difficulties in bringing
proceedings to assert that they have mental capacity or that a particular act is not in their
best interests. These dilute the right of access to a court under the MCA to a point where
its protection is more likely to be ‘theoretical and illusory’ rather than ‘practical and
effective’, and thus will not be compliant with the ECHR (Airey v. Ireland [1979] ECHR 3 §24).

THE BREADTH OF THE GENERAL DEFENCE/GENERAL AUTHORITY (SS 5
AND 6 MCA)

10. The vast majority of decisions concerning a person’s care and welfare will be made
under ss5-6 MCA – sometimes referred to as the ‘general defence’. This general defence is
an unusual legal mechanism inasmuch as it does not purport to provide a formal legal power,
and yet in practice it provides caregivers – public and private – with tremendous
discretionary power to interfere with a person’s ECHR rights whilst protecting them against
liability. The European Court has stated that where ‘discretion capable of interfering with
the enjoyment of a Convention right’ is conferred upon a person, then the procedural
safeguards will be highly relevant to whether or not a person’s Article 8 ECHR rights have
been violated (Buckley v The United Kingdom [1996] ECHR 39 §76). During the passage of the
MCA through Parliament, the Making Decisions Alliance, amongst others, raised concerns
that what was at the time known as the ‘general authority’ ‘gives statutory recognition to a
‘closed relationship’ that will not be monitored by any third party, and may therefore be
open to abuse’. They wrote:

....the draft Bill currently lacks any accessible mechanisms by which an individual may
challenge a formal or informal assessment of capacity made about them. Although an
individual assessed as lacking capacity can make an application to the Court of Protection to
challenge any declaration made by the Court on the basis of this assessment ...the Bill does
not explain how Ministers envisage that a person who may have a significant mental disorder
can be supported to make such an application.

11. Many other respondents to the consultation on the Draft Mental Incapacity Bill
including Mencap, the Alzheimer’s Society, the Law Society, the British Association of Social
Workers, People First, the British Psychological Society, the Disability Rights Commission,
the National Autistic Society and Age Concern – expressed concern that this ‘general
authority’ contained insufficient safeguards. The government responded by renaming it the

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'general defence', but it is not clear how this cosmetic alteration changes the fundamental reality that the mechanism is not subject to any routine monitoring and may be open to abuse.

THE IMPORTANCE OF ADVOCACY

12. Professor Clements told the Joint Committee on the Draft Mental Incapacity Bill that:

...for every one person with mental capacity difficulties to get to court, there are probably 100,000 who have no access because the mere concept of stepping into a solicitor’s office is intimidating, as it is for all of us, and the reality is that people with mental capacity difficulties never take the first step. (Oral evidence, Questions 620-639)

He regarded advocacy as being ‘utterly fundamental’ in rectifying this difficulty. Likewise, the Making Decisions Alliance and others pushed for statutory advocacy to be included in the Bill, and so the Independent Mental Capacity Advocacy (IMCA) service was created. We acknowledge that the IMCA service may bring many benefits to people who receive a referral. However, we contend that this provision does not provide an adequate procedural safeguard for decisions made under the MCA, nor does it surmount the access to justice problems.

13. This first issue is the referral mechanism, to which the Committee’s attention has already been directed taken to in oral evidence. The annual reports of the Department of Health on the IMCA service describe large variations in the number of referrals between different geographical areas, which could not be explained by population size. In 2011 the Department commented that ‘The duty to refer people who are eligible to IMCAs is still not understood in all parts of the health and social care sector’. The referral must come from the person charged with assessing capacity and making a best interests decision, and in addition to the problem that sometimes such decision makers are ignorant of the IMCA requirements under the MCA, there is considerable scope for discretion in this referral. For example, regarding whether or not a person is suitably represented by family – there is no automatic provision for advocacy where a person disagrees with their family’s viewpoint, nor any real clarity over the definition of Serious Medical Treatment, or where a person might benefit from advocacy during care reviews or safeguarding investigations. The key problem with the referral mechanism is that those who have the least understanding of the MCA, those who are least in tune with its values of including and supporting a person to participate in decisions, or those who seek to avoid any external scrutiny and possible challenges to their decisions, are among the least likely to make an IMCA referral at a time when it might be most beneficial.

14. The second issue is that the role of an IMCA, as conceived by the statute and regulations, is very unclear regarding when they should challenge a decision-maker on behalf of a person who is alleged to lack mental capacity. The regulations give IMCAs an equivalent power to make a complaint or application to the Court of Protection as any another person involved in their care and welfare (r7 The Mental Capacity Act 2005 (Independent Mental Capacity Advocates) (General) Regulations 2006 SI 2006/1832). However, outside the specific context of s39D(8) MCA and the DoLS, they have no clear duty to do so. The annual reports on the IMCA service from the Department of Health, and data collected by Lucy Series under the Freedom of Information Act 2000, suggests that IMCAs may exercise this power only very rarely. Whilst allowing that there may be problems with the quality of

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the data, it appears that as few as 0.3-0.5% (during 2009-12) of IMCA referrals may result in a complaint of some kind being made, and between 0.06-0.09% (during 2009-12) result in an application to the Court of Protection.

15. In oral evidence to this Committee, IMCA providers appeared to interpret their role as requiring them to ‘challenge when the decision is not in the person’s best interests’ (Q112). They described making this decision as taking good judgment, care and training. Yet, extraordinarily, there is a dearth of guidance from the Department of Health or any other authoritative body on when they should do so. Recalling that the recent ECHR case law described above lays down a right for ‘P’ to challenge a declaration of incapacity in court, or to bring a dispute with a third party decision maker to court, and that this right must be practical and effective, we submit that IMCAs should be encouraged to take a much more pro-active role in helping people to exercise these rights. The right to obtain access to a court to air disputes under the MCA should not rest on the IMCA’s judgment call as to best interests, but the person’s own opposition to some measure which interferes with his ECHR rights and which is premised upon his ‘incapacity’. We acknowledge that this will require revising the guidance given to IMCAs, and it may also require substantial increases in resources available to them to do so. Issues around commissioning by local authorities, giving rise to conflicts of interest in helping to initiate litigation against them, may also need to be addressed.

HEALTH AND WELFARE DISPUTES AND COURT INVOLVEMENT

16. The responsibility for helping to bring disputes under the MCA before a court does not solely fall on IMCAs, however, as many cases will not involve an IMCA. In Glass v UK [2004] ECHR 103 the European Court of Human Rights held that public authorities also have a responsibility to bring serious disputes concerning medical treatments before a court, rather than relying upon families to initiate legal action. Unfortunately, the point at which a public authority must refer a dispute to the Court of Protection for adjudication is very poorly defined in the MCA Code of Practice and the case law. The Code of Practice says that ‘cases where there is a doubt or dispute about whether a particular medical treatment will be in a person’s best interests’ should go to Court [8.18]. Where and of disputes that do not involve medical treatment it says only that ‘an application to the Court of Protection may be necessary for... particularly difficult decisions [or] disagreements that cannot be resolved in any other way’ [8.3]. This leaves many unanswered questions, chiefly: how serious must a dispute be to warrant an application to the Court of Protection, who is responsible for bringing it there, and who must be in dispute?

17. In A Local Authority v A (A Child) & Anor [2010] EWHC 978 (Fam) §66 Munby LJ reviewed the powers of local authorities under the common law, under ss5-6 MCA, and in relation to community care service provision and concluded that:

...none of these sources of local authority engagement with someone like C confers on the local authority any power to regulate, control, compel, restrain, confine or coerce. They are concerned with the provision of services and support.

He went to assert (at § 68) that ‘if a local authority seeks to control an incapacitated or vulnerable adult it must enlist the assistance of either the Court of Protection or the High Court’. This seems in many ways a somewhat surprising conclusion – as any exercise of s5 MCA will involve a best interests decision maker exercising some degree of control over a
person’s life, and s6 in particular does appear to provide a defence for acts which control, compel, restrain, confine and coerce. The critical question, which has not been answered by the courts or the guidance, is: what is the extent of control which s5-6 MCA permits a person to exercise without authority from a court?

18. In the landmark domestic ruling London Borough of Hillingdon v Neary & Anor [2011] EWHC 1377 (COP) §33, where Jackson J held that:

‘Significant welfare issues that cannot be resolved by discussion should be placed before the Court of Protection, where decisions can be taken as a matter of urgency where necessary’

Jackson J outlined two principles for when cases concerning the MCA should be taken to court by public authorities:

‘21. The first is that it is undoubtedly lawful for actions to be taken by families and local authorities, acting together on the basis of a careful assessment of the best interests of incapacitated persons.’

‘22. The second central principle concerns cases of disagreement. The ordinary powers of a local authority are limited to investigating, providing support services, and where appropriate referring the matter to the court. If a local authority seeks to regulate, control, compel, restrain, confine or coerce it must, except in an emergency, point to specific statutory authority for what it is doing or else obtain the appropriate sanction of the court’

The difficulty with this principle is that it does not provide for situations where professionals and family are in agreement as to a person’s capacity and best interests, but where the person themselves is not. Under such circumstances, it is unclear how a person could realistically access justice to contest a declaration of incapacity or bring their dispute with best interests decision makers before a court. They would be unlikely to have an IMCA if families and professionals were involved and in agreement, and the Neary ruling appears not to require public authorities to refer such cases to a court. Yet surely, under the ECHR, a person’s rights to access justice to assert their capacity cannot hinge on something so arbitrary as whether or not their relations and professionals have fallen out? We submit that there must be much clearer guidance to public authorities regarding what disputes under the MCA must be proactively referred to a court, including in situations where only the person who is alleged to lack capacity disagrees with any course of action.

LITIGATION CAPACITY

19. Once an application to the Court of Protection has been made, the Court of Protection Rules 2007 appear to presume (contrary to the spirit of the MCA) that ‘P’ (the person who is alleged to lack capacity) will lack the ‘capacity to litigate’ and a litigation friend must be appointed (rule 141). The rules do provide for situations where ‘P ceases to be a person who lacks capacity to conduct the Proceedings’ (rules 147 and 148), but these appear to presume that he never had that capacity in the first place. It is unclear from the rules whether there is any point at which P may instruct his lawyer to argue, on his behalf, that he does have the capacity to litigate.
20. Litigation capacity is a critical element in enabling a person to contest any declaration of incapacity or air any dispute regarding his best interests. Where a litigation friend is appointed, they will instruct their lawyer to act in their best interests, and although they will convey to the court any views that person holds they will not necessarily oppose any measures which the person themselves objects to (see RP v UK [2012] ECHR 1796). For example, in the cases Re E (Medical treatment: Anorexia) (Rev I) [2012] EWHC 1639 (COP) and A NHS Trust v Dr. A [2013] EWHC 2442 (COP), E and Dr A both opposed being forcibly fed under the MCA, but their own lawyers argued that it was in their best interests. We submit that this dilutes the adversarial nature of proceedings in the Court of Protection, and may mean that a person’s right to assert that they have capacity and oppose any measure in their best interests is less effective than it would be if they were able to instruct a lawyer to argue that case on their behalf as forcefully as possible.

21. We suggest that the Committee might consider an alternative arrangement for supporting people with mental disabilities in litigation, which has been adopted in the Republic of Ireland. In 2007 the Irish Human Rights Commission intervened in a settled case (Legal Aid Board v District Judge Patrick Brady and the Northern Area Health Board & Others) concerning the Irish Legal Aid Board’s refusal to fund a guardian ad litem to support a person with learning disabilities in care proceedings to remove their child. The Commission argued that the CRPD required ‘reasonable accommodations’ to enable persons with disabilities to participate in litigation, and suggested that a guardian ad litem was such an accommodation. Crucially, however, they also argued that in accordance with Article 12 CRPD, the role of a guardian ad litem for an adult should be to ‘bring his or her skills to bear in order to determine the wishes and instructions of the adult party and to relay same to the Court’, and to ‘advocate on behalf of the adult in a manner which respects the dignity of the adult and which best vindicates the party’s right of effective access to the Court’. They submitted that ‘the constitutional rights to self-determination and autonomy, coupled with the guarantee of equality before the law’ required that their role be limited to this, rather than – as in the case of a child – to advocate for their best interests. In response to this case the Irish Legal Aid Board made arrangements for a new role (not a guardian ad litem) of supporter, to help a person to understand the nature of any litigation they were involved in and to give instruction to their solicitor (all documents available here: http://www.ihrc.ie/enquiriesandlegal/amicuscuriae/intellectualdis.html). It is suggested that the Committee should recommend that the government investigate the establishment of such a role – which could perhaps be played by IMCAs – to support people involved in litigation in the Court of Protection who are able to communicate their wishes and preferences, but who would be unable to understand and communicate instructions to their lawyers without additional specialist support. This would have the additional advantage of alleviating the pressure on the Office of the Official Solicitor in relation to Court of Protection welfare disputes, and would enable those supporting a person in litigation to be more locally based and able to meet with them in person.

HUMAN RIGHTS: THE RULE OF PERSONAL PRESENCE

22. The European Court of Human Rights has recently developed one final important element in relation to legal capacity and access to justice: the ‘rule of personal presence’. It is already a well established part of the fair trial guarantees of the ECHR that a party to a case has a right to be physically present before proceedings whose purpose is to establish questions of fact which relate to that person (Ekbatani v Sweden [1988] ECHR 6). In a series of cases, most recently Lashin v Russia [2012] ECHR 63, the European Court has emphasized in order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
that this ‘rule of personal presence’ also applies for proceedings concerning people deprived of legal capacity. There is, therefore, a strong presumption in favour of a person physically participating in proceedings which concern his legal capacity, or at least having some personal contact with the judge deciding his case. In *X and Y v Croatia* [2011] ECHR 1835 § 84 the European Court held that ‘judges adopting decisions with serious consequences for a person’s private life, such as those entailed by divesting someone of legal capacity, should in principle also have personal contact with those persons.’ In part this was to help the judge come to a personal view as to the necessity and proportionality of any interference with a person’s rights.

23. The physical presence of a person in proceedings concerning their legal capacity has a dual role – to enable them to advance their case and contest any evidence as a subject of proceedings, and to enable a judge to come to an independent view as to their ‘capacity’ as an object of proceedings (*Shtukaturov v Russia; X and Y v Croatia; Salontaji-Drobnjak v Serbia* [2009] ECHR 1526). This latter element of personal presence is regarded as especially important as a safeguard against arbitrary loss of legal capacity resulting from overreliance on medical evidence. Domestically, the importance of judges coming to an independent view of a person’s capacity was reinforced in *CC v KK and STCC* [2012] EWHC 2136 (COP) where unusually (§ 44) ‘P’ gave oral evidence in court, enabling the judge to reject the medical and social work unanimous evidence that Mrs KK lacked mental capacity. In *Re SB (A Patient; Capacity to Consent to Termination)* [2013] EWHC 1417 (COP) the judge commented that in his experience the medical evidence as to capacity was usually determinative, but in those cases P generally did not give evidence (§ 36). The judge stated that ‘my assessment of this case has been enormously illuminated by her attendance and by the considerable oral evidence which she has given’ (§ 29); he found that SB had mental capacity. We submit that consideration should be given to recommending revising the Court of Protection Rules to include a presumption that the judge will meet the person who is alleged to lack capacity.

The Deprivation of Liberty Procedures

The Human Rights Context and the MHA/MCA Interface

24. Article 5(1)(e) of the European Convention on Human Rights permits deprivation of liberty on grounds of ‘unsoundness of mind’, provided it is carried out in accordance with a procedure prescribed by law. The European Court of Human rights has held that for an Article 5(1)(e) deprivation of liberty to be lawful, unless it is an emergency, objective medical evidence of a true mental disorder must be presented to the competent authority, the mental disorder must be of a kind or degree warranting confinement, and deprivation of liberty must be a proportionate response in the circumstances. The detaining authority must review the detention at intervals, and anyone detained under Article 5(1)(e) must have the right, himself or through a proxy, to challenge detention before a court or tribunal with the power to order discharge.73

25. Under English and Welsh law, where a person is detained under the Mental Health Act 1983, objective medical evidence (two medical reports, or in an emergency one medical

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26. Persons detained in hospitals under the Mental Health Act in hospitals or care homes may be forcibly medicated, but this is subject to a system of second opinion safeguards. The medication must be certified to be appropriate by a Second Opinion Appointed Doctor (SOAD) appointed by the Care Quality Commission. The limitation of this safeguard is that the patient is not entitled to a second opinion until three months have elapsed from the first time when medicine was given during that period of detention (the so-called three month ‘stabilising period’). Article 8 of the European Convention protects the right of physical integrity as part of the right to respect for private life. In X v Finland the Strasbourg Court held that:

Forced administration of medication represents a serious interference with a person’s physical integrity and must accordingly be based on a “law” that guarantees proper safeguards against arbitrariness. In the present case such safeguards were missing. The decision to confine the applicant to involuntary treatment included an automatic authorisation to proceed to forced administration of medication when the applicant refused the treatment. The decision-making was solely in the hands of the treating doctors who could take even quite radical measures regardless of the applicant’s will. Moreover, their decision-making was free from any kind of immediate judicial scrutiny: the applicant did not have any remedy available whereby she could require a court to rule on the lawfulness, including proportionality, of the forced administration of medication and to have it discontinued.  

27. The Court went on to say that ‘the absence of sufficient safeguards against forced medication by doctors deprived the applicant of the minimum degree of protection to which she was entitled under the rule of law in a democratic society.’ It may well be that the existence of the three month stabilising period under s 58 of the Mental Health Act 1983 will have to be revisited in the light of X v Finland, but the second opinion procedure in relation to medicines may otherwise be sufficient to provide the minimum degree of protection to which patients are entitled under the rule of law in a democratic society.

28. The Deprivation of Liberty procedures were introduced to achieve compliance with the European Convention on Human Rights, in response to the Strasbourg Court’s ruling in HL v
United Kingdom that the UK government was in breach of Article 5. HL had been sedated and taken to hospital to be admitted informally, without using the detention procedures in the 1983 Act. The facts that HL was incapable of consenting to admission, was not resisting going into hospital, and had not tried to leave, were held to be irrelevant to the question of whether he had been deprived of his liberty. The Court refused to treat the absence of dissent as valid consent:

‘The right to liberty in a democratic society is too important for a person to lose the benefit of Convention protection simply because he has given himself up to detention, especially when it is not disputed that that person is legally incapable of consenting to, or disagreeing with, the proposed action.’

The Court held that the level of control over HL’s residence, his movement, his treatment, and his contact with the outside world was of a sufficient degree and intensity to amount to a deprivation of liberty. This being so, Article 5(1)(e) had been breached because the deprivation had not been authorised in accordance with a procedure prescribed by law. Article 5(4) had also been infringed, since HL had been unable (himself, or through a proxy) to seek review of the lawfulness of his detention before a court with the power to order discharge.

29. The Mental Health Act 1983 already contains an extensive regime of procedures to detain on grounds of mental disorder, but the Government sought to achieve ‘Convention compliance’ by introducing the new procedures under the Mental Capacity Act 2005. These procedures or safeguards would apply only where the patient (‘P’) was or was about to be deprived of liberty, but not when the interference with rights fell short of amounting to a deprivation of liberty. The DOL procedures make it lawful to deprive a person of their liberty, but only if (a) there is a standard or urgent authorisation (under the new Schedules A1 and 1A to the 2005 Act) or (b) the Court of Protection has ordered a deprivation of liberty in deciding a personal welfare matter, or (c) an application has been made to the court and it is immediately necessary to save the person’s life or to perform a vital act.

30. Schedules A1 and 1A are voluminous and densely drafted, with 205 paragraphs extending over 53 pages, all for one power. This is more than is devoted to the two complete regimes of powers to detain offender and non-offender patients under Parts II and III of the Mental Health Act 1983. They are very difficult to follow, even for experts, and are certainly not user friendly for service users and their families. The standard and urgent authorisations apply to deprivations of liberty in hospitals, but also, unlike the Mental Health Act, allow detention in care homes. If a person is deprived of liberty in any other setting, an authorisation from the Court of Protection is necessary. A considerable number of the cases on whether there has been a deprivation of liberty have involved settings other than hospitals or registered care homes. In an understandable effort to avoid opening the

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76HL v United Kingdom (2004) 40 EHRR 761, 81 BMLR 131


78 For example A Local Authority v A, B and the Equality and Human Rights Commission: A Local Authority v C, D and E and the Equality and Human Rights Commission [2010] EWHC 978 (Fam) Munby J; Re MIG and MEG [2010] EWHC 785 in order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
floodgates of potential applications to the court, the courts have adopted a narrow approach to deprivation of liberty, most notably in the Cheshire West case where Lord Justice Munby (as he then was) adopted the comparator approach whereby a person would not be treated as being deprived of his or her liberty if s/he would be subject to those restrictions because of her disability wherever s/he was resident. This interpretation, whilst understandable in the context of avoiding opening the floodgates, would contravene Article 14(2) of the United nations Convention on the Rights of Persons with Disabilities which requires States Parties to ensure that if persons with disabilities are deprived of their liberty through any process, they are, on an equal basis with others, entitled to guarantees in accordance with international human rights law and shall be treated in compliance with the objectives and principles of this Convention, including by provision of reasonable accommodation. Person with disabilities include people with mental health and intellectual disabilities. If the existence of a deprivation of liberty depends on the level of the person’s disability, to the extent that the more disabled a person is the less likely they are to be deprived of their liberty, and the availability of procedural protections for human rights depends on the existence of a deprivation of liberty, Article 14(2) must surely be engaged and infringed.

31. The decision of the Supreme Court in the Cheshire West case is eagerly awaited. Since Cheshire West the Strasburg Court has ruled in a number of cases on deprivation of liberty, most notably Kedzior v Poland79 and Stanev v Bulgaria80, and in those cases has laid great emphasis on the issue of whether the person is free to leave without permission. Mr Stanev was allowed to go home (which was a considerable distance away) on leave, but he was subject to an obligation to return if and when required. He was held to be deprived of his liberty.

32. The availability of safeguards depends on whether the person is believed to be, or to be about to be, deprived of liberty. This requires an assessment by those operating the procedures of a highly technical question of fact and law which is ultimately to be decided by the European Court of Human Rights. As that court has repeatedly emphasised, the distinction between a deprivation of liberty, which requires authorisation by a procedure prescribed by law, and a restriction of liberty, which does not, is a matter of ‘degree and intensity.’ The starting point must be the ‘concrete situation of the individual’ and a whole range of criteria must be taken into account such as the ‘type, duration, effects and manner of implementation of the measure in question.’81 In Stanev v Bulgaria the Grand Chamber remarked that ‘the process of classification into one or other of these categories sometimes proves to be no easy task in that some borderline cases are a matter of pure opinion’, but that ‘the Court cannot avoid making the selection upon which the applicability or inapplicability of Article 5 depends.’82 There has been a massive development of English case

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79 Judgment of 6 October 2012, para 57
82 Judgment of 17 January 2012, para 115.

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law on the finer nuances of deprivation of liberty, and as we have seen the issue has become highly technical.

33. Once a person is deprived of liberty s/he may be given treatment without consent or restrained. If the person is detained under the MCA, it is likely that s/he will be treated under the authority of s 5, and possibly restrained under s 6. If that person was detained under mental health legislation s/he would be entitled to a second opinion in relation to the forced medication, and restraint and seclusion are governed by detailed guidance in the Mental Health Act Codes of Practice. 83

34. In the CQC’s report “Monitoring the use of the Mental Capacity Act Deprivation of Liberty Safeguards in 2011/12” they express concern that ‘The use of restraint is not always recognised or recorded as such, and because of this it is not easy to monitor.’ 84 The CQC also report ‘wide variation in how local authorities carry out their functions as supervisory bodies, and express concern that ‘It is not clear whether people’s views and experiences of the Safeguards are being heard in care homes and hospitals.’ 85

35. The wide regional variations in the use of the procedures in both England and Wales are a recurrent theme in the statistical reports. In England, the East Midlands has consistently had the highest rate of completed applications, currently at 48.6 per 100,000 whilst London had the lowest rate at just 14 per 100,000. The national average for England as a whole is 28.3 per 100,000. 86 The lack of precision about what is a deprivation of liberty, is likely to be a significant factor in explaining these variations. 87 There has been a year on year increase in the number of applications completed for Deprivation of Liberty Safeguards (DoLS) since they were first introduced in 2009/10. There were 11,887 applications in 2011/12, which represents a 4% increase on the 11,382 in 2010/11 which in turn was 27% increase on the 8,982 in 2010/11. The 2011-2012 figures represent a 66% increase on the 7,157 applications in 2009/10 (the first year of the new safeguards). 6,546 of the 11,887 applications in 2012-2013 were granted. The number of people subject to a standard authorisation at the end of the quarter had also increased in each quarter since the safeguards were introduced, from 536 at the end of June 2009 to 1,976 at the end of December 2011. However, between the end of December 2011 and March 2012, 1,667 people were subject to a standard authorisation at the end of March 2012 (a fall of 16%). 88 This decrease followed a noticeable increase in the number of people subject to a standard authorisation at the end December 2011/12 (an


85 2013, pp 6-7


88 Id.

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increase of 17%), and the number has subsequently declined further so that at the end of June 2013, 1575 people were subject to standard authorisations.89

36. In Wales, the procedures are monitored by Healthcare Inspectorate Wales and the Care and Social Services Inspectorate Wales.90 They too report wide regional variations in the use of the procedures, and have consistently emphasized their concern at the ‘apparent lack of access to clear information and knowledgeable support, the low level of referrals to IMCAs to support the relevant person, their family and friends and rare use of reviews to challenge individual authorisations or to confirm that they continue to meet needs.’91

37. In 2012 the HIW/CCSW found that two supervisory bodies received no applications during the year. In total 545 applications were made in Wales under the Safeguards in 2011-12. This resulted in the granting of 298 standard authorisations. 261 urgent authorisations (110 health, 151 social care) had already been put in place by the managing authority at the same time as an application for a standard authorisation was made. Thirty-nine per cent of care home applications for standard authorisation were preceded by an urgent authorisation and 68 per cent of health applications for standard authorisation were preceded by an urgent authorization.92

38. In terms of the effectiveness of the procedures as safeguards, the key issue is the ability of P or her or his proxy to seek review of the need for the deprivation. The English figures do not give information about this. The Welsh reports do record this, but note that the implementation of reviews is very low. In 2012 out of 298 authorisations granted, only 30 were subject to review: ‘Reviews of the qualifying requirements for an authorised deprivation of liberty were held infrequently. Over the last three years, the number of reviews has varied, with 30 held in 2011-12, 22 in 2010-11, and 65 in 2009-10.’93 The HIW/CCSW rightly view the infrequent use of reviews of qualifying requirements as giving rise to concern, and have referred to the need to explore the reasons for this more deeply. The HIW and CCSW say that they have taken account of the direct individual experience of relevant persons through discussion with inspectors and reviewers, but recognise that ‘despite the valuable insight individual experience brings, it does not support robust conclusions about the general effectiveness of the Safeguards.’94 We commend the approach


90 Healthcare Inspectorate Wales and the Care and Social Services Inspectorate Wales, Deprivation of Liberty Safeguards Annual Monitoring Report for Health and Social Care April 2010 – March 2011


91 Ibid., 2011 Report p 5.

92 2012 Report, p 11.

93 Id.

94 Ibid., pp 4-5.

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of the HIW/CCSW in seeking to explore the effectiveness of the DOL procedures as safeguards by looking at the use of the review procedures. It is important to gather adequate information about this aspect of the procedure, rather than looking solely at patterns of use of the procedures to get people into homes and hospitals.

39. The ability of individuals under the MCA to challenge themselves, or though a proxy may well be inadequate to meet the requirements of Article 5(4) of the European Convention. Only three people are eligible to seek review by the local supervisory body: P, P’s representative ‘R’ who is appointed by the supervisory body, or the ‘managing authority’. If P or R (if s/he is unpaid) request it, a s 39D IMCA must be appointed, and the IMCA has a duty to take such steps as are practicable to help P and R understand their rights to seek review, and to help them to exercise their right to seek review and to exercise their right to apply to the Court if it appears that either P or R want to exercise that right. The problem here is that the supervisory body, who is being asked to carry out the review also appoints R and instructs the IMCA. It is questionable whether this process allows R or the IMCA to possess the requisite independence of the detaining authority.

40. There are several problems with the DOLs regime from the Convention point of view.

1. The use of the concept of deprivation of liberty as the gatekeeper concept for the procedural protections means that a person’s Article 8 rights may go without protection. Moreover, there is such uncertainty and potential for subjective judgment over the meaning of the concept of Deprivation of Liberty that two patients whose situations are identical may be treated very differently, one having the benefit of the procedures and the other not. This may be one explanation for the wide regional variations. Other commentators have noted the difficulties arising from the uncertainty over what is a deprivation of liberty95, and these uncertainties are, it is submitted, unlikely to be resolved by any decision of the Supreme Court in the Cheshire West case.

2. Even though people may be deprived of their liberty using the procedures, they do not have the same safeguards around treatment which potentially engages Article 8 as patients who are detained under the Mental Health Act. There needs to be effective protection of Article 8 rights.96 If the patient, relative, carer or nominated person is objecting to anti-psychotic medication or ECT given without consent there should be a second opinion. Controls and guidance at least as protective as that provided under the Mental Health Act Code of practice should be provided for patients subject to such interventions as restraint and seclusion.

95 Isabel Clare, Marcus Redley, Amanda Keeling, Adam Wagner, Jessica Wheeler, Michael Gunn, Anthony Holland, ‘Understanding the Interface between the Mental Capacity Act’s Deprivation of Liberty Safeguards and the Mental Health Act’ University of Cambridge 2013.

96 X v Finland (Judgment of ECtHR 3 July 2012); C v A Local Authority [2011] EWHC 1539 (Admin) (The ‘blue room’ case); J Council v JU and others [2012] EWHC 3531 (COP).

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3. The fact that the supervisory body (which is the detaining authority) potentially has such influence over the appointment of P’s representative R, and is the body which instructs the IMCA who to support P and R in any challenge.

4. The Mental Health Act (MHA) allows an individual to bring a challenge to detention regardless of their capacity, and regardless of whether the challenge is in their best interests. In this sense the MHA is more ‘rights-based’ than the Mental Capacity Act where a patient’s litigation friend may decide that it is not in her or his best interests to bring a challenge.

5. There is sufficient overlap of ‘eligibility’, such that in many cases professionals have to make a choice of which statutory regime to use, and case law has developed on the circumstances where each regime should be preferred. This causes unnecessary difficulties and uncertainties in decisions about care.

2 September 2013

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97GJ v The Foundation Trust and others [2009] EWHC 2972 (Fam) 2 November 2009 (Charles J); C v Blackburn and Darwen Council and a Care Home [2011] EWHC 3321 (COP) (Peter Jackson J)

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The Forget Me Nots – Written evidence

Report of a special meeting of The Forget Me Nots

This special meeting was held to discuss the impact that the Mental Capacity Act has had on members of the group.

The meeting was held at the request of the Dementia Engagement and Empowerment Project (DEEP). DEEP had been approached by the House of Lords Select Committee on the Mental Capacity Act 2005 to find out the experiences of people with dementia.

This report will be submitted as written evidence to the House of Lords Select Committee.

About The Forget Me Nots

The Forget Me Nots are a group of people with dementia from the area of East Kent, who meet regularly in Canterbury. The group aims to help people with dementia get their voices heard. It is supported by the local NHS Trust, and co-chaired by Reinhard Guss, Consultant Clinical Psychologist, Elisabeth Field, Clinical Psychologist, Mental Health Services for Older People and Keith Oliver who has dementia and is Kent and Medway Primary Trust Dementia Service User Envoy.

The group aims to help organisations, including the local NHS Trust to improve the quality of service they offer to people with dementia. The group believes it is vital that the opinions of people living with a diagnosis are heard by those who make decisions. The group also functions as a network, where people can meet others with a similar diagnosis and get to know them better.

The Forget Me Nots is a key group within the Dementia Engagement and Empowerment Project (DEEP). DEEP provides support to existing and new ‘involvement’ or ‘influencing’ groups of people with dementia across the UK. The project is being developed in collaboration with people with dementia, and includes opportunities for sharing resources and ideas, building the capacity of groups, setting up networking opportunities between groups, supporting existing groups to mentor emerging groups and, in time, for groups to form a national network of collective voices.

About the meeting

Nine members of the Forget Me Nots attended the meeting.

Nada Savitch from Innovations in Dementia and DEEP chaired the meeting. We split into two groups to discuss issues around the Mental Capacity Act – these groups were facilitated by Nada Savitch and Reinhard Guss.

Lord Hardie and Lord Swinfen along with Judith Brooke (clerk to the Committee) kindly attended the meeting to listen to the views of people with dementia.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
The Forget Me Nots – Written evidence

Five students helped the meeting run smoothly and took notes.

We discussed such issues as:

- Who makes decisions in your life? Are there decisions which you make for yourself? Are there decisions which are made by others on your behalf?
- If someone has helped you to make decisions or made a decision for you ... What happened? What did it feel like?
- Have you had any experience of someone assessing your ‘mental capacity’?
- Have you had experiences of Lasting Power of Attorney?
- Have you had experiences of telling your bank or other organisations that you have dementia?

What members of The Forget Me Nots said

This report summaries what was said at the meeting across the two groups.

Direct quotes are used but (for privacy) they are not attributed to named members of the group.

The conversations did not necessarily happen in the order set out below.

About making decisions

The group all agreed that they all have the capacity to make decisions, but that this is slowly changing. And other people might be making more decisions on their behalf.

“It’s like the door is slowly shutting”

“It moves more to my wife now than me”

“My wife tells me what to wear … she didn’t do that before I got dementia”

Some members feel they are still able make the same decisions. Others feel less confident.

“I was the main decision-maker … but now my wife can think it out better than I can”

“I still make decisions; they just might not be the right ones” “I don’t have confidence in my decisions”

“Everything’s just the same, except I can’t think some things out now”

Some members found this change in decision making difficult as it means they are losing independence.

“My wife has made decisions for me … it doesn’t feel good. I want to make decisions”

Some members thought sometimes decisions were made about them for the right reasons.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
The Forget Me Nots – Written evidence

“I want to be protected as I become more fragile, less able to make decisions”

“In my world I’m not different [to how I was before dementia] – I think I’m still alright”

“It’s easier to take if you can see that the decision is being made for your own benefit”

People felt that it is important that information is presented in a way that is easy to understand.

**Telling officials that you have dementia**

Members of the group felt that they had been treated differently when they had told people they had dementia.

Sometimes this was for the better – one member had been in Lloyd’s bank (which is working with Alzheimer’s Society) and had had a helpful response. Others had good experiences too.

“We have a great relationship with the bank and they help us a lot, we always see the same person”

Others felt they were patronised and discriminated against for having dementia, or just being older.

People had different thoughts about the needs or desirability of telling officials about their diagnosis.

“I don’t mind telling people, I just don’t think it’s necessary yet”

“I wouldn’t tell the bank until I was really downhill”

“I don’t mind telling people, I just don’t want sympathy”

“With utilities, if they don’t know you have dementia, how can they help you?”

There was a suggestion that details of lasting power of attorney could be added to Alzheimer’s Society ‘I have dementia’ cards.

**Being assessed for capacity and best interest**

People felt some apprehension about being assessed for mental capacity. They felt it fluctuated and was especially dependant on whether you were feeling anxious or depressed at the time.

“It makes me nervous”

Some people did feel that people were judging their mental capacity.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
The Forget Me Nots – Written evidence

“I feel I might be prejudged if I’ve told someone I have dementia”

The concept of ‘best interest’ is a difficult one, and many people are not aware of it.

“Best interest … that’s difficult to define”

**Bad experiences of Mental Capacity Act**

Some members of the group referred to friends and relatives who had bad experiences under the Act.

There was particular concern about cases where there was no Lasting Power of Attorney and people had to work through a solicitor.

“The wife can’t access the money – she can’t get the money out without going to the solicitor”

“It costs £5000 a year”

“Why can’t the carer go back and get the power of attorney?” “Is there a standard fee?”

“Do you have a choice of solicitors?”

There was a feeling that that Act does not always support those it says it is there to protect. And that the balance between protecting people and stopping the minority that may exploit people with dementia was sometimes wrong.

“The Act seems to be working against the innocent rather than protecting them”

“How can we deal with this unscrupulous minority without inhibiting the scrupulous?”

“Are people judged not to have capacity too soon?” “The Act focusses too much on exploitation”

**Lasting Power of Attorney**

Lasting Power of Attorney was one aspect of the Mental Capacity Act that was familiar to most people at the meeting, although many people did not have one, and some people were not clear about what was covered.

“Is the idea that it’s just financial?”

“Older people might think it’s not for them”

“It might be more important for someone with young onset dementia, less so for someone in their 80s – we don’t really mind what happens to our money”

Most people agreed that it was a very good idea and should be done early on.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
The Forget Me Nots – Written evidence

“Make your wishes know now!”

“It’s important to write things down”

“Do it early and put it on one side”

Many people felt that the process was complicated and difficult to understand.

“It’s difficult, it feels like going up a mountain”

“It takes a lot of thought – it’s lengthy”

“It took me three months to get to grips with it”

“The big pile of paper needs to be reduced”

In many people’s experience it was an expensive process that needed a solicitor.

“You need advice from a solicitor”

“I drew it up myself and got a lawyer to sort it for me”

“It cost me about £1000”

“A list of approved solicitors would be good”

There was a feeling that although it’s a good thing to do, people put it off or don’t get round to it.

“It’s too difficult – it put’s people off”

“It’s expensive and daunting”

“There needs to be more encouragement for people to do it – we tend to park it”

“It’s not just us who put it off, it becomes a taboo subject – family members don’t want to talk about it either”

“We like to live for the day – we don’t want to discuss this all the time”

There is confusion about how power of attorney operates with utilities and banks.

“Even if the attorney goes to the bank or the utilities, they don’t know that the power of attorney has been given”

“The utilities will only speak to the person whose name is on the account – they won’t take the spouses word for the fact that they have power of attorney”

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
People felt that organisations such as banks and utilities should have access to information about who holds power of attorney.

“Utilities should have access to that information”

“They should create a register where you can check who has power of attorney”

Some people felt that power of attorney should be an automatic right within marriage or part of the marriage vows. But others felt that there were complications due to divorce and people living together.

“In case of marriage, shouldn’t be assumed?”

It was agreed that it can sometimes be difficult to find someone to take on the attorney role.

“Decisions should be made by someone you trust”

“It’s hard to find people you trust enough or who want to do it”

“I don’t want to burden my children”

People felt that couples should make Lasting Power of Attorneys together.

Information about the Mental Capacity Act

There was also a feeling that there is too little information available about the Mental Capacity Act and Lasting Power of Attorney in particular.

“There’s not enough information about it generally”

“200,000 people need this information”

“Lots of people with dementia are older – how do they know about it?”

“Why does everything have to be online?”

“There needs to be more advertising”

“We had a lawyer turn up to our post-diagnostic support group to explain”

“It’s important to be informed by someone you trust’”

But people agreed that at diagnosis there is often an overload of information.

The voluntary sector, especially CAB and Alzheimer’s Society were thought to have a role. [The Alzheimer’s Society does have a good information sheet about the Act]

“The Alzheimer’s Society could have a role in informing people about the Act”

“Banks and CAB etc should be there to help you fill in the forms”
Language

Some people didn’t like the term ‘Mental Capacity Act’ because of the association with mental illness.

It was felt that labels such as ‘carer’ and ‘sufferer’ can foster stereotypes

“We still care for our partners even when we have dementia”.

30 October 2013
In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Dr Martin Gee – Written evidence

My name is Dr Martin Gee. I am a psychiatrist and currently Chair of the West Midlands s12/Approved Clinician Panel. We also hold the medical DoLS register in the West Midlands. I would like to focus my comments mainly to involvement of others in medical decisions and the medical aspects of DoLS.

The Mental Capacity Act in general

Overall I think this is a good piece (except DoLS) of legislation that needs little reform. The only area that I think needs strengthening is the involvement of others when someone is unable to make a medical decision. It is inferred that friends or relatives should be involved but there is no guidance about who this should be and how someone can be usurped if they were thought not to acting in the incapacitated persons best interests. There is a pecking order for “nearest relative” in the mental health act and I think this could be an appropriate guide for whom hospitals should try to contact to make a substituted decision. If it is felt that there is a conflict I think this should be evidenced and then someone else lower down on the list is consulted instead. I do not think “displacement of nearest relative processes” would be required in this circumstance.

DoLS

DoLS is confusing and unwieldy and needs reform. I think there should be clear advice about the distinction between “restriction” and “deprivation” of liberty. I know that judges have agonised over this but my own view is that the distinction lies in the intensity and duration of the impositions. I think it should be very rare for urgent interventions imposed on someone without capacity in their best interests to be regarded as deprivations but the threshold is very much lower for impositions that are occurring on a day to day basis. Objections to the impositions by patients or their relatives/advocates clearly take matters into the DoLS arena.

The DoLS forms for urgent and planned needs are far too complex. The Mental Health Act forms are an example of how these forms should be. The urgent DoLS is effectively a holding power and all it really needs to confirm is that the person lacks capacity and that there is an urgent need for the deprivation because of risk which should be identified. The form could perhaps explain why if the person has a mental disorder that the MHA is not considered. This can be done on 1 side of A4. The more substantive DoLS process does have address eligibility and best interests in more detail but this can probably be done effectively on 3 sides of A4.

4 (3) of the 2008 regulations state that medical DoLS assessors have to have initial training by the Royal College of Psychiatry and annual refresher training. The on line royal college initial DoLS training has not be up dated since 2009 and is not fit for purpose. It also gives the Royal College sole provider rights regardless of the quality of cost of training that they provide. This cannot be correct. There is also no guidance on how refresher training can be quality controlled.

Recommendation: Medical assessor powers for DoLS become an extension of the S12 role so that all s12 approved doctors are automatically DoLS medical assessors. S12 doctors are

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Dr Martin Gee – Written evidence

trained in the interface between the MCA & the MHA and they already have sophisticated initial training, refresher training and re approval processes that exist and are regulated. DoLS training can easily be incorporated into this and in many cases is already there. Approval is usually for 5 years and it would widen the pool of available DoLS assessors and stop RCPsych from being the sole provider of initial training. Best interest assessor training is probably still best kept at local authority level.

I hope you find this useful.

18 July 2013
General Medical Council – Written evidence

Introduction

1. The General Medical Council (GMC) is the independent regulator for doctors in the UK. Our role is to protect, promote and maintain the health and safety of the public by ensuring proper standards in the practice of medicine.

2. We do this by controlling entry to the medical register and regulating all stages of medical education and training. We also determine the professional values and standards that underpin good medical practice and we take firm but fair action where those standards have not been met - if necessary, by removing the doctor from the register and removing their right to practise medicine.

3. This memorandum sets out the GMC’s views on the implementation of the Mental Capacity Act 2005 (MCA) to date, and how we are helping doctors to understand and comply with the MCA as part of our wider work to promote good practice.

Overview and Context

4. The MCA impacts on all doctors working with or caring for adults (16+) who lack mental capacity (or have impaired capacity) to make their own decisions about health, social care and financial matters in England and Wales.

5. The MCA helpfully makes clear who has authority to make decisions in certain situations; who must be consulted about decisions when a patient lacks capacity; the legal status of advance decisions to refuse treatment; the non-clinical factors that must be taken into account in determining a patient’s best interests; the approach that should be taken to resolve serious disagreements about treatment and care, as well as the legal protections available to doctors (and others) for reasonable decisions made in good faith. Otherwise, for the most part, the principles in the MCA and Code simply enshrine in statute what most doctors will recognise as good practice in decision-making, as set out in our guidance, for example the importance of supporting patients to make their own decisions wherever possible.

6. However, there are some areas of practice where application of the principles and definitions of the MCA and supporting code may have had unintended consequences which might warrant some clarification of, or amendment to, the legal framework. These issues relate primarily to the application of the ‘best interests’ principle (see paragraphs 21-23 below); and uncertainties about the boundaries between the MCA and other legislation relating to mental health issues and decisions affecting young people between 16-18 years old (see paragraph 28 below).

Implementation

7. The GMC has a key role to play – working alongside other organisations – in providing leadership and guidance to the medical profession. It is a core part of our statutory duties to provide guidance on good practice and we try to ensure that our guidance supports doctors to work in a way that is consistent with UK law.

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8. Our core guidance, Good medical practice (GMP), defines what it means to be a good doctor in the UK. This includes doctors’ responsibilities to keep up to date with, and follow, the law and other regulations relevant to their area of work (GMP, paragraphs 11-12); and to work effectively with patients to make decisions about their treatment and care (paragraphs 31-34, 46-49). We also provide explanatory guidance which gives more detail on how to apply the standards in practice.

9. Clearly, doctors have a legal duty to have regard to the MCA and its supporting Code of Practice in their day-to-day decisions about the treatment and care of patients who lack capacity. So it is important that doctors take steps to familiarise themselves with those legal principles, and with the provisions of the Code which are of most relevance to their areas of practice. We have drawn attention to this in our explanatory guidance (see below) and in a number of earlier published statements about the MCA around the time that it came into force.

10. Our explanatory guidance on Consent: patients and doctors making decisions together, Treatment and care towards the end of life (EOLC) and 0-18 years: guidance for all doctors all make reference to the MCA and include decision making principles that are consistent with the provisions of the MCA and Code. The EOLC guidance explains in some depth the relationship between the legal framework and the ethical obligations set out in the guidance. See in particular paragraphs 15-16, 40-46, 67-74 and the legal annex.

Regulation

11. The GMC has a key role to play – again working alongside other organisations – in supporting doctors to provide a good standard of care consistent with their professional responsibilities.

12. In addition to providing guidance, we produce a wide range of materials aimed at helping doctors provide better care by showing GMC guidance in practice. Much of our existing materials cover issues in day-to-day practice affecting the care and treatment of patients who lack capacity to make their own decisions or express their preferences and values. For example our online interactive learning tool – Good Medical Practice in Action – includes a number of case studies that show how to communicate effectively with and support patients and their families, where the patient lacks or has impaired capacity (http://www.gmc-uk.org/gmpinaction/)

13. We have produced a dedicated website which helps doctors to provide better care for people with learning disabilities. It expands on the guidance in GMP and Consent: patients and doctors making decisions together and demonstrates how it applies to practice when supporting, treating and communicating with patients with learning disabilities.

14. We have also produced a decision making flow chart which illustrates (using brief vignettes) how to apply our guidance to patients’ end of life care in cases where they lack capacity. This helps doctors to ensure that they are complying with the legal as well as the ethical framework, while providing the best possible care to patients.

15. In 2012, we launched our Regional Liaison Service which is working across England, supplementing the work of our existing offices in Scotland, Wales and Northern Ireland, to

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engage with large numbers of doctors, medical students and patients and providing guidance and challenge on professional standards.

16. Our education functions include responsibility to set out the knowledge, skills and behaviours that medical students must demonstrate by the time they graduate. These standards are published in Tomorrow’s Doctors (TD09) which includes, for example, an expectation that ‘a graduate will be able to carry out a consultation with a patient….assess a patient’s capacity to make a particular decision in accordance with legal requirements and the GMC’s guidance.’ (TD09, paragraph 13). We also state that:

20. The graduate will be able to behave according to ethical and legal principles. The graduate will be able to:

(f) Understand and accept the legal, moral and ethical responsibilities involved in protecting and promoting the health of individual patients, their dependants and the public – including vulnerable groups such as children, older people, people with learning disabilities and people with mental illnesses.

(g) Demonstrate knowledge of laws, and systems of professional regulation through the GMC and others, relevant to medical practice, including the ability to complete relevant certificates and legal documents and liaise with the coroner or procurator fiscal where appropriate.


Decision making and the impact of the MCA

18. The GMC is not best placed to determine whether the MCA has achieved all of its aims. Such feedback as we do have about the impact of the MCA is not systematic and has been obtained through our engagement with, and written enquiries received from, the public, educators and the medical profession.

19. That said, the (albeit limited) evidence we have would suggest that in some areas the MCA has achieved its aims in terms of providing clarity about who can make decisions for patients who lack capacity and how those decisions should be approached. It would seem that, at least in some areas, an effective structure of advocacy support for patients has been put in place.

20. However, there may be areas in England and Wales where there is a low level of understanding about specific legal requirements in the MCA, for example around Independent Mental Capacity Advocates (IMCAs), whose role is to provide crucial protection for the most vulnerable patients. We have had a number of enquiries from IMCAs or IMCA providers suggesting that some doctors are poorly informed about the circumstances in which a patient is entitled to have an IMCA appointed and the rights of an IMCA to be involved in the decisions about the patient’s treatment and care.
21. The ‘best interests’ principle in the MCA states that any act done or decision made on behalf of an adult lacking capacity must be in their best interests. Based on queries raised with us from time to time by doctors and others, we believe that there are certain unintended consequences from the definition of ‘best interests’ and challenges in deciding how far it is reasonable to extend the principle to include actions that benefit third parties.

22. The MCA allows actions and decisions that benefit people other than the patient, as long as they are ‘in the best interests of the patient’. The Code provides the example of taking and testing a patient’s blood to check for a genetic link to cancer within their family. However questions have arisen in relation to:

- Education and training – the application of the ‘best interests’ principle may create difficulties in relation to the education and training of health (and other) professionals when an adult lacks capacity to decide whether, for example, to allow medical students to be involved in their care or agree to visual/audio recording of aspects of their treatment and care for educational purposes. It is difficult to argue that it is ‘in the best interests of’ the patient, if she gains no direct benefit from contributing to another person’s education and training.

- Third party exposure to blood borne diseases – if a clinician undertakes a clinical procedure where he or she is at risk of exposure to a serious communicable disease, for instance as result of a ‘sharps’ injury, it may be helpful to them to know about, for example, the patient’s HIV status before deciding whether to take prophylactic treatment. If the patient lacks capacity and is unlikely to recover capacity quickly (or at all) so that they can provide information or give their consent to testing, it cannot be said to be ‘in the best interests of the patient’ to take and test a blood sample if it is solely for the benefit of the clinician. However, for the injured clinician, the uncertainty can be extremely distressing and may lead them to take prophylactic treatment, with serious side effects, unnecessarily.

23. It might be possible to argue, where the ‘third party benefits’ from a proposed action align with a patient’s previously expressed preferences and values, that the action is in the patient’s best interests. Although the MCA and Code are silent on this point, a court decision in 2010 stated that, ‘the wishes which P would have formed, if P had capacity, which may be altruistic wishes, can be a relevant factor’. Even so, this does not address situations where a patient never had capacity or where (as may well be the case in practice) nothing can be ascertained in a timely manner or at all about a patient’s preferences and values. In order to put matters beyond doubt, it would be necessary to make changes to the MCA or seek clarification through revisions to the Code. It is interesting to note the gradual extension of the definition of ‘best interests’ through policy developments such as the DH publication Legal issues relevant to non-heart beating organ donation – this may be an alternative practical way of achieving some resolution to these difficult issues.

**Understanding and local implementation of the MCA**

24. When the MCA was implemented, it seemed that the regional implementation advisors were an effective vehicle for assisting both systems and professionals within each Strategic Health Authority in England and Local Health Board in Wales to comply with the MCA. On a number of occasions, in the years immediately after the MCA came into force, we were able to refer enquiries from doctors, IMCAs and others, to these regional advisers (and the national support teams) as a source of support and practical advice in understanding and implementing the requirements of the MCA and Code. It is difficult to identify any...
current central or local points of support and advice for those wishing to improve their knowledge or learn from other examples of good practice.

25. Baroness Neuberger’s review of the Liverpool Care Pathway and the Parliamentary and Health Service Ombudsman and Local Government Ombudsman’s Report Six lives: the provision of public services to people with learning disabilities are two of a number of recent high profile reports which highlight the importance of the clinical community having a good level of knowledge about their responsibilities under the MCA and the benefits and protections that the legal framework provides for vulnerable people.

26. The Care Quality Commission’s report, published in March 2013, on its monitoring of the Deprivation of Liberty Safeguards Providers also found that providers and commissioners of services for vulnerable adults must improve their understanding of the MCA and the Safeguards.

Other legislation

27. Some of the enquiries we receive suggest that many professionals have struggled to understand how best to meet their obligations towards patients where their assessment and treatment may be covered in part by the Mental Health Act 2007 (and its formal processes for decision making and review) and in part by the MCA principles when treating and managing their physical conditions. As well as the different decision making frameworks, there is tension between the underlying aims of these pieces of legislation – the MHA is focused primarily on ensuring public safety, whereas the MCA focuses on empowering patients to make their own decisions and choices.

28. In addition, there is overlap between the MCA (which applies to individuals aged 16 - 18) and the Children Acts 1989 and 2004 (which apply to people up to age 18). It is not clear in what circumstances it would be reasonable to apply the provisions of the MCA in preference to the Children Acts (or vice versa). It can be difficult to reconcile the MCA’s guiding principles - which focus on empowering people to make their own decisions, as much as they are able and wish to do so, with the child welfare principles underpinning the Children Acts - which allow a young person’s wishes and preferences to be overridden in some circumstances. These may be areas where additional guidance with examples of good practice, perhaps as supplements to the Code of Practice, could be helpful both to those expected to apply the different legal frameworks and the young people (and their parents/carers) whose rights and interests may be affected these decisions.

4 September 2013
General Medical Council follow up note to the Committee on the Mental Capacity Act 2005

Introduction

1. The General Medical Council (GMC) welcomed the opportunity to provide the Committee with both written and oral evidence on the Mental Capacity Act (MCA).

2. As agreed during Paul Buckley’s oral evidence on 29 October, this brief note provides supplementary information to the Committee, in relation to a question from Baroness Barker about working with the Royal College of General Practitioners (RCGP) and others.

How we work with others

3. As we said in our submission, the GMC has a key role to play in supporting practising doctors to be aware of their professional responsibilities in this area - working alongside other organisations including the RCGP.

4. We carry out a wide range of activities to help doctors to understand their professional duties in this area – see page 8 of our submission. This includes promoting, with support from the Colleges and others, the range of online materials that illustrate how the standards in our guidance can be applied in practice (http://www.gmc-uk.org/guidance/20706.asp).

5. Much of this material covers issues in general practice involving the care of patients who lack capacity to make their own decisions or express their preferences and values. A particularly well used resource is our interactive learning tool – Good Medical Practice in Action (GMPiA) – which includes a number of case studies showing how to communicate effectively with and support patients and their families within a general practice setting (http://www.gmc-uk.org/gmpinaction/). Our data shows that since April 2013, the case studies relating to patients with impaired capacity have received over 2,000 (external) visits.

6. GMPiA and our other online resources are promoted directly to doctors, alongside the guidance, through our network of Regional Liaison Advisers in England and our offices in Wales, Scotland and Northern Ireland. This often involves collaboration with the medical royal colleges, local Trusts and other local/national organisations, where we have shared in-year priorities for action to support improvements in professional practice and local services.

7. Currently the issues around consent and decision making capacity, advance care planning and the role of family members, are areas where there is strong local demand on us for more resources and support to help doctors understand their responsibilities and how to meet them in practice. We respond positively to such requests wherever we can.

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8. We are currently considering what opportunities can be created or may arise in 2014 for us to collaborate with the Colleges, Faculties and others, to deliver a targeted programme of work aimed at supporting doctors to provide high quality, personalised care for vulnerable older people and patients who are approaching the end of life. This is likely to focus on a few key issues around effective communication and shared decision making, advance care planning and working across service boundaries to meet the needs of patients and their families. The RCGP and a number of other organisations have already expressed strong interest in working with us on these issues, many of which are directly relevant to the MCA.

21 November 2013

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
TUESDAY 29 OCTOBER 2013

Members present

Lord Hardie (Chairman)
Lord Turnberg
Baroness Andrews
Baroness McIntosh of Hudnall
Baroness Barker
Baroness Hollins
Lord Swinfen
Lord Alderdice
Baroness Shephard of Northwold
Lord Faulks

Examination of Witnesses

Paul Buckley, Director of Education and Standards, General Medical Council, and
Marc Seale, Chief Executive and Registrar, Health and Care Professions Council

Q210 The Chairman: Good morning. You were present during the previous session, so
you have heard my warnings about broadcasting and transcription of evidence. Welcome to
this second evidence session today. Can I start by asking the same question I asked of the
previous witnesses? How does the Mental Capacity Act feature in the delivery of your
functions, and how do you relate to each other and others with regulatory or inspection
functions with regard to the Act? Can I start with Mr Buckley?

Paul Buckley: Thank you very much. The GMC’s function is to protect, promote and
maintain the health and safety of the public by ensuring proper standards in the practice of
medicine. Our focus is on professional standards. It is largely in that role that we highlight
the importance of the Act to doctors. It features in our standards work. It features in our
educational work. We set outcomes in relation to undergraduate education, but also we
approve postgraduate curricula that refer to the Act and the importance of understanding it.
It features in our education work and it also features in the outreach work that we do

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where we engage with the profession. Ultimately, of course, it may feature in our fitness-to-practise determinations where we are taking action where there has been serious breach of good medical practice. It is very strongly reflected in our functions.

In terms of how we relate to other organisations, you heard from David Behan about the memorandum of understanding that exists between the CQC and the GMC. There are opportunities for exchanging of information where the need to do so arises.

**Marc Seale:** In relation to the Health and Care Professions Council, there is a strong interrelationship. Firstly, we are a regulator of individuals and we set the standards of education and training for those individuals. We are essentially the systems regulators of university programmes, and we require the universities to ensure that graduates who are coming onto the register meet the required standards and proficiency. That includes an understanding of the legislation relevant to their particular profession.

As a regulator of around about 320,000 individuals, we expect all of those individuals, whatever profession they are from, to have an up-to-date understanding of the relevant legislation. We expect those individuals to be up to date. If they are not and if there are complaints or allegations they are not meeting those standards, we pick that up in our fitness-to-practise process.

This is also very important in terms of what we do as a regulator in relation to our communications. We spend a lot of time meeting and talking to the universities, talking to employers and actually meeting individual registrants. We would expect, as an organisation, to discuss any problems with all three groups to see whether there is a problem out there and, therefore, whether we need to adjust our standards. There is a loop between setting standards, approving university courses, running fitness to practise and, as a regulator, going back to those individuals and making sure those standards are adhered to.

**Q211 Baroness Shephard of Northwold:** This question was also asked of the earlier witnesses. The failings of hospitals and care services, as we all know, have received huge publicity recently. In your view, to what extent is the apparent failure to implement the Mental Capacity Act in these settings the result of wider failings in healthcare professional and care standards? Is it symptomatic, in other words?

**Paul Buckley:** Perhaps I could start with that. Yes, there is a connection. Similarly to Mr Behan, we would start from the point of view that the primary failing is in relation to professional standards. The failure to understand or apply principles within the MCA is a symptom of that more fundamental professional failing. The primary failing is not in relation to the Act itself. It is one remove from the underlying professional failure to act in accordance with the standards that we set. Clearly, however, there is a relationship, because if the importance of the Act were properly understood, perhaps we may not see some of these failings that have been so well documented, not least this year.

**Marc Seale:** In relation to the professions that we regulate, so far we have not been involved in the recent debacles that have come to light. However, as a regulator you must never be complacent. Just because you have not detected something does not mean it is not there. It might mean that you do not have the systems and processes to detect it in the first place. That is very much the philosophy of the way we run the HCPC.

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You also have to divide the world very much in terms of professional regulation. The professional regulation we run in the UK generally is very good at training highly competent individuals who come on to the registers; the vast majority meet those standards throughout their professional careers and deliver fantastic care. There is a very small minority of individuals who do not. In terms of what we do, we pick those individuals up in fitness to practise. Again, what we are looking for is whether there are themes. Are there things going on amongst professionals? We then have to go back to the universities and the professional bodies and increase those standards. Standards are at the heart of professional regulation.

However, we have to be acutely aware of the issue of more and more of health and care being delivered by non-professionals. This is a good thing because the cost of that delivery is better. It is more efficient, and as a regulator we absolutely support that, but unless you have statutory standards—particularly standards of education and training—there is no way that you can hold these individuals to account and stop them moving around. If you move, particularly, into the care arena, we as a regulator are very adamant that statutory regulation of one sort or another should be brought into that area. Until that is done, there is a missing piece from the jigsaw and we will continue to be unable to do anything as a statutory regulator.

Baroness Andrews: Can I follow up on that? The weight of material and methodologies you put out in terms of guidance is obviously hugely significant and very important for the regulation of the profession. Mr Behan’s evidence was that, although those frameworks were absolutely vital, what really counts is the quality of experience and the interchange between the patient, and the understanding that the professional has of a condition, whether it is a communication difficulty or whatever else. The question he asked was, “How do they know they are delivering the care required by the best application of the MCA?” What would you say that looked like in relation to the weight of stuff that you are producing in terms of standards, regulation and identifying failure? Do you agree with him about that?

Paul Buckley: One of the challenges that everyone faces in this area is the sheer amount of information. What can be an intimidating amount of information that doctors and—I am sure—other healthcare professionals feel they may need to be able to get to grips with and assimilate, if they are to be effective. One of the things that we have tried to do is boil this down to a few simple principles and make those accessible to doctors in a way they can really engage with. We are in the middle of a huge programme of work to try to become more effective at that. However, we know from research we have done that one of the barriers to effective practice is sheer information overload. Rather than presenting doctors with a tome on the Mental Capacity Act, what we are trying to do is simplify and find ways, perhaps through new technology and other means, of engaging doctors in some of the simple principles they can feel confident on. If they can base their practice on those principles, by virtue of doing that they will be on the right side in terms of the MCA and other pieces of legislation.

Q212 Lord Alderdice: You have both talked about the importance of undergraduate as well as postgraduate education and training. One thing that has become apparent in the evidence we have received is that when it comes to psychiatrists there is a reasonable understanding of mental capacity, but with general practitioners and others it is less...
impressive. I am a little puzzled why the GMC does not seem to require that all medical schools have a professor of psychiatry, so that that side of understanding—not just of the Act, but of the approach—is imbued in young doctors in their training and not left to postgraduate. In some cases, where there has been a professor of psychiatry for 30 years or more, it has been abandoned in recent times—yet this is an area where the GMC has a very important and powerful role.

**Paul Buckley:** Our approach has been to set outcomes but to allow some flexibility in the way that medical schools deliver on those outcomes. We do have a specific outcome in relation to assessing a patient in relation to a capacity issue. We are very clear that any medical student graduating needs to be able to do that. How the medical school decides to arrange themselves and what people they employ and so on is—we have taken the view—a matter for them. We are absolutely clear about the outcome that we are seeking.

We do know, from anecdotal evidence, that many new graduates find this an enormously challenging and worrying area of practice for them. We are looking at the impact of our guidance in the new *Tomorrow’s Doctors* at the moment. One of the questions we are asking the research team to look at systematically is this question of how confident graduates feel about practising in relation to this outcome, because we would like to have greater evidence than the anecdotal evidence we have. There is an issue, but we are very clear on the outcome we are seeking, which is a mandatory outcome for all graduates in that area.

**Q213 Lord Turnberg:** You told us, quite rightly, that your main role is in education and training, development of curricula and making sure standards are high and then, at the end of the day, when someone fails, holding them to account. However, what we keep hearing all the time is that the Mental Capacity Act and its practice require a change in culture. Do the regulators have a role in changing the culture and, if so, how?

**Paul Buckley:** We certainly have a role in promoting a partnership culture between doctors and patients. That is something the GMC has been doing for some 20 years or more. We also have an outreach programme, as I mentioned at the beginning, where we are going out to doctors to engage them in conversations about good practice and our principles. Yes, we do have a role to play in changing culture and we are actively seeking to become more effective in doing exactly that.

**Marc Seale:** On this whole issue of culture, I use the phrase in relation to organisations. My experience of being a chief executive is that, if you want to change the culture of an organisation, it is a very slow and incredibly challenging process, which takes decades rather than weeks or months. However, the role of the regulator is fundamental in the concept of professionalism: our expectations, as citizens and society, of what we expect a professional to do and how to behave in certain situations. Our role is absolutely critical in ensuring that professionalism is taken up by those individuals going into the programme.

For example, about 20% to 25% of our complaints come from professionals who are concerned about the performance of their fellow professionals, which is one of the core things that professionals do. We have to ensure that those individuals not only set their own standards but require their fellow professionals to meet those standards as well. We have a big role in that relationship and how those individuals behave in particular
organisations. I am not sure that we have a direct influence on the way the culture of those organisations develops or is controlled.

Q214 Baroness Hollins: May I ask a supplementary question? I wanted to follow up on Lord Alderdice’s question in the context of culture. It seems to me that the culture in medical schools is actually part of the problem. We keep hearing that doctors are not very good at this. It is all very well for it to be an outcome, but I wonder whether, in line with your idea about reducing things to basic principles, you could actually advise medical schools on those schools where they are more effective at producing those outcomes. They might find their priorities are in the wrong place in terms of whom they are employing, because medical schools are focusing more much on their research outputs than their teaching outputs. That would be my possible criticism of your approach.

Paul Buckley: All medical schools will have areas of strength and areas where they need to develop what they do. In relation to the overall issue around education and training, it has taken some time for the system to catch up with the fact that we have an ageing population whose needs are changing. As it happens, this very morning an important report has been published, Securing the Future of Excellent Patient Care, about the future shape of training in medicine in the UK by Professor David Greenaway, the Vice-Chancellor of Nottingham. One of the things that report says is that we need doctors, as they come through, to be much better equipped to deal with patients in the round in a more holistic way and to be skilled not just in their individual specialty but a broader range of professional competencies, which will enable the kind of personalised care that Mr Behan was referring to.

You are right to pose the challenge to the regulator. I guess what I would say is that the system is responding—albeit perhaps not as quickly as everyone would want.

Marc Seale: Could I add an important point that I have not mentioned? For any professional, it is not only about your initial education. It is not a case of, “That is it; get on with it,” and then you work in a particular area for 40 years. The whole concept of continuing professional development—the idea that you should refresh, renew and expand your education throughout your career—is a vital role that regulators have to play. Without that, there will be problems. As a regulator, we require registrants to undertake what we call continuing professional development. We audit them and we expect those individuals to improve throughout their career. The challenge is that you can start off as somebody who has literally come off a programme of physiotherapy on day one and know a little bit about everything; 30 years later, you could be a Nobel Prize winner in a particular area of genetics as a clinical scientist. It is not just a question of keeping up to date with the basics of what you do as a professional, but also, if you have specialised, you must make sure you meet those standards.

As a regulator—not just in the UK, but across the world—one of the big challenges we have is ensuring that those professionals maintain and enhance their professionalism and those standards throughout their career, not just focusing on the initial dollop of education they get when they are in their late teens and early twenties.

Q215 Lord Faulks: Mr Buckley, you say in your evidence that, for the most part, the Mental Capacity Act reflected what was enshrined in good practice. You also say that the feedback you have in medical settings is not systematic; it tends to be somewhat anecdotal.

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There are two things I would like to ask you. Firstly, albeit that this is somewhat anecdotal, can you give us particular examples where you think there is some evidence of doctors falling short in their application of the Mental Capacity Act? Is there a particular area?

I will declare an interest here or make the admission that I am a lawyer. The second question is this. On a number of occasions, doctors are asked to help the court on the question of capacity, but courts are uncertain as to which sort of doctors should be giving that evidence. Do you think all doctors should be able to assist the court with capacity? What do you think about either of those two points?

Paul Buckley: On the first point, as to what areas doctors find difficult, the whole area of treating patients with learning disabilities is one that doctors have, from time to time, struggled with. Certainly, the discussions we have had with, for example, Mencap, have highlighted the fact that there are some real challenges for doctors in providing effective care for that group of patients. That is one of the reasons we have developed particular learning materials and a special part of our website that is devoted to good principles around the care of patients with learning disabilities. That is one thing that we are doing to try to address that gap.

In relation to the second point, there may have been a tendency in the past to think issues around capacity were for particular specialties. If you were in another specialty—not psychiatry or care of the elderly—it was perhaps not so much of an issue. Certainly, however, I was very struck by a statistic in the report from the Royal College of Physicians of London last year, which pointed out that one in four inpatients in hospital has had a diagnosis of dementia. What that underlines is that these issues around capacity are issues for all of the medical professions who are in contact with patients—not for particular specialties. That is why the shape of training review report, which I referred to earlier, is so important in saying to the profession, “These are issues for all doctors, not just for particular groups.”

On the particular issue of who should give evidence in court, all doctors need to understand what is required in terms of assessing capacity, because that is something any doctor in touch with patients might need to be able to deal with. Whether that would be appropriate in terms of expert witness evidence, I do not think I am probably best qualified to pronounce on.

Q216 Lord Swinfen: Mr Buckley, you report that you receive enquiries from IMCAs and IMCA providers, which suggests that some doctors are fully informed about the IMCA entitlements of patients. As a professional regulator, how do you respond to such enquiries?

Paul Buckley: In terms of the immediate enquiry, we will point the enquirer to, for example, our guidance on consent and what is said in that document reflecting what is in the MCA. They are then clear that the professional regulator does regard this as an important issue and that we have issued guidance to the profession on it, and that then empowers them to go back and have the conversations that they need to have, understanding where we are coming from. That is the first thing that we are doing in terms of the immediate enquiry.
In terms of the broader programme of work, as I said, we are reaching out. We have this new network of regional liaison advisers, who are now offering workshops to doctors in response to demand. Consent is one of the areas where there is a demand for their services. This is not the MCA specifically, but the issues around consent, which, of course, are reflected in the MCA. Our colleagues have delivered well over a dozen workshops to several hundred doctors in this year alone. There is enormous demand for doctors to understand what their responsibilities are and, going back to my earlier point, to try to communicate this in a simple way so that they can immediately see what it is they need to be doing. One of the challenges for us is to see how we can harness new technology and deliver information to doctors in a way they can readily understand. Those are the two things that we would do in relation to your point.

Q217 Baroness Barker: When we received evidence from other medical bodies such as the BMA and, in particular, the Royal College of General Practitioners, they flagged up to us that your colleagues in general practice have a particular problem when it comes to involvement in assisting people with advanced decisions, because they do not know the status of their involvement. Crucially, however, they do not know how that decision will be communicated through the system. I wondered if we might ask you—not necessarily now—to respond to us. You might talk to us, or do a written submission, about how your work and the work of other people like the RCGP might work together for the benefit of patients.

Paul Buckley: I would be very happy to provide a submission on that. We are working closely with the RCGP over their proposal to extend the length of their training from three years to four years. One of the reasons they are seeking to extend the length of that training is so that there can be better coverage in the curriculum of this sort of issue.

Marc Seale: May I make a couple of points? On this question around standards and guidance, as a regulator, if we were getting lots of questions on guidance it would seem to indicate to us there is a problem in terms of how they are written or constructed. Your standards and guidance must not be set in concrete, because the profession is developing on almost an hourly basis.

We have a constant Forth Bridge-type exercise where we are revising our standards on a three-year cycle. For example, if there are a lot of questions from a profession and they do not understand what they should do, we would revise our standards or guidance—or, indeed, if, for example, you were to come up with a suggestion or recommendation in terms of what should be included in our standards, we would go round a route of consulting on those and making sure they are fit for purpose.

In terms of advanced decisions to refuse treatment, that is actually one of the areas where, in fact, we are aware of a potential issue out there in relation to the professions that we regulate. It is very much to do with the context of where some of our professions work. In relation to paramedics, they can be in situations—I am aware of one of these situations—where they go to a house late at night and there is an individual who has had a heart attack, and there are very distressed relations who are saying, “We have this document that tells you what to do.” The paramedic has the dilemma: “Do I get on intervening and trying to deal with that patient, or should I sit back and read this 20-page rather legal document about what I should do?” Our advice has been that what they should do is get somebody to phone...
back to the ambulance station and read out what the document says while the other individual gets on treating the patient.

In certain contexts, we do have issues like that, which go back to the legislation. However, as I said, if it becomes a big issue, what we would do is change our guidance to the individuals that have to use it.

Baroness Andrews: May I pursue what you have just said about the potential for four-year GP training instead of three years? This has come up before. Is it being driven in part by the changes in demography and the whole shape of health and care services having to shift towards an older population, where these issues will become much more dominant, or are there other factors? One of the issues, following the earlier evidence, is to what extent the notion of personalisation involves a different professional attitude and different professional skills. We had the debate earlier about whether it was attitude or skill; is this something that is going to be a greater part of GP training as well?

Paul Buckley: As I recall, the educational case for extending training in general practice was driven by three things. One was greater exposure to mental health as part of GP training. The second thing was greater exposure to paediatrics as part of general practice training. The third was a sense that those coming through newly on to the GP register were competent to do what they needed to do, but they were not confident about doing it. There was a strong feeling in the Royal College that in order to get general practitioners who were more confident, they needed to have a bit longer in their training programme to give them a more secure basis on which to go on and practise. It was a combination of factors, but, certainly, mental health and its relationship to demographic changes is definitely a factor in that.

Baroness Andrews: It is a real opportunity for the principles and practices around the MCA to begin to be more embedded in general practice training, perhaps.

Paul Buckley: One could see that, yes.

Q218 Baroness McIntosh of Hudnall: Mr Seale, you probably heard the question Lady Barker asked of the preceding witnesses about this difficulty that we have seen arising in evidence of the MCA being used inappropriately occasionally—perhaps frequently—as a safeguarding mechanism, rather than an enabling mechanism. It is very easy to see why people faced with a potentially difficult situation where risks are involved might take a rather risk-averse approach to how that situation is resolved. As regulators, how do you see your role in trying to ensure that the balance between avoiding disaster and enabling free decision-making is struck?

Marc Seale: The first thing is that we try to be an evidence-based regulator. If there is an issue out there, as a regulator we need to go and collect it, talk to our stakeholders, consult and find out what the scale of the problem is. To date, we have not seen any evidence there is a problem out there in terms of the professionals we regulate by looking at fitness to practise. Fitness to practise, however, is the safety net at the bottom of the system. Things have to be very bad before you get picked up by fitness to practise.
If the view of the Committee is that there is a problem out there, we would take it away and look to see what the problem is. We would then have to feed it back into either long-term education or, in terms of the short term, going to the professional bodies and, in certain circumstances, writing to every relevant registrant that we deal with. Again, because we are a multi-professional regulator, if you take some professions—I should not pick on professions—such as clinical scientists or biomedical scientists, it is potentially less of an issue than if, let us say, you are forensic psychologist working in a secure hospital.

Baroness McIntosh of Hudnall: I was struck by something Mr Buckley said a moment ago in response to Lady Andrews about the difference between competence and confidence; it is quite relevant here, is it not? In fact, people can know what they should do and still feel very uncertain about how they do it. Clearly, that can be addressed in training. However, going back to your earlier observations about continuing professional development, how do you model, through your regulation, to the people who are registered with you, what good continuing professional development might include and how you know when you have done it? This issue about making a difficult decision in a very volatile situation would be a good example, would it not, of where somebody’s experience would be as relevant as their training?

Marc Seale: That is quite a complicated question; can I try to divide it up?

Baroness McIntosh of Hudnall: I am sorry.

Marc Seale: One of the key things in terms of the confidence of a professional is how long they have been working. There is a period for, let us say, the first two or three years somebody is on the register in which they might not be as confident as somebody who has been around for 20 years. Certainly, for example in Scotland they have a process called Flying Start, where they support newly graduated professionals into the system, particularly in the first year, when they can contact people; they can phone people up and actually get advice in terms of what to do. This is a really important stage in terms of making sure those individuals end up as confident professionals.

In the other area, there is a sense that the Holy Grail of regulation is this issue about how you ensure the continuing competence of individuals throughout their career. There are various systems—and this is not a UK problem; it is a global issue. First of all, what we have to work out is what professionals should do throughout their career that enhances their practice and skills. We use a system called continuing professional development, and we allow the professional to decide from the portfolio of things what they need to do in terms of CPD. If they do not do the CPD, we can remove them from the register; we stop them from renewing their registration. There is a stopgap.

However, the question is this: does CPD actually reflect continual professional competence? If we wanted to, we could set up an incredibly complex system; we could ask each registrant to come in to attend a process, which maybe lasts for a couple of days, and run them through a system to say, “Yes, they are competent.” The problem is the cost of doing that. There is the cost of those individuals turning up and the backfilling and all the other things you have to do. In a sense, no regulator anywhere has cracked that problem. Certainly, however, we are looking for a solution—though we have not come up with one so far.
Q219 The Chairman: Why do you not follow the Scottish model of the Flying Start in England?

Marc Seale: Again, one of the challenges of being a regulator is we regulate professionals across four different systems of the NHS—whether it is Northern Ireland, Wales or Scotland. Certainly, it is my observation as a regulator that Scotland is sometimes able to implement very quickly the systems and processes they have, because it is a much smaller system, and often quite radically in terms of how they deliver health and how they get their professionals on board. It is certainly something we think is an extremely good idea and, if we had the opportunity to speak to England, Wales and Northern Ireland, we would say, “This is a good idea; what do you think about doing it?”

The Chairman: Would that be something for the GMC or the BMA?

Marc Seale: I have enough challenges dealing with my own regulation to think of advising the GMC. That is your prerogative.

Paul Buckley: There is an important point coming out of what Mr Seale has said in relation to the UK dimension. Of course, the MCA is legislation for England and Wales, but, as UK regulators, we have to talk in generic terms that fit with the UK dimension. One of the criticisms made of regulators sometimes is that people cannot see specifics pieces of legislation, like the MCA, reflected in them. That is because we often have to deal with legislation in generic terms. We are going to be looking at whether, in determinations that are relevant to practice in England and Wales, we could refer specifically to the MCA in order to give it profile so that, while reflecting the principles, we are also talking in terms of the specific piece of legislation that is relevant. This is a slight aside, but I thought it was important to mention that.

The Chairman: It just occurred to me that, if there is a system of encouraging new doctors, supervising them and helping them to give them confidence in the first year and beyond, it seems, in principle, to be quite a good system. I wondered if it had been thought of in England and Wales.

Paul Buckley: There are a number of programmes like that. For general practitioners they have something called a first-five programme, which is for the first five years after they get on to the GP register. In other specialties, there are things called clinical fellowships, which people may take after they are on the specialist register to provide them with additional support. This is something that is now recognised; the system is responding.

Q220 Lord Alderdice: I have one question for you, Mr Seale, and then a question for both of you. The submission by the GMC reflects positively on the Government’s mental capacity implementation programme. Have professionals regulated by the HCPC had a similarly positive experience? To both of you, is there a continuing need for central or local points of support and advice on the MCA?

Marc Seale: I do not know, because none of the professions or professional bodies have approached us about it. That does not mean there is not a problem and, certainly, as we go through our cycle of meeting the professional bodies on a formal basis, it is one of the issues that we will be addressing. However, we have had no information or feedback on there being an issue at the current moment in time.
Lord Alderdice: To both of you, is there a continuing need for particular points of support nationally or locally?

Paul Buckley: I would see the advantage of there being a home where, if there are issues that arise, those can be taken delivery of and dealt with—so yes.

Marc Seale: We will very much wait for the Committee to produce its report and see what your advice is on that and, if it is appropriate, take it forward. However, we do not have an opinion at this current moment in time.

The Chairman: Thank you very much indeed. This has been very helpful.
Generate – Written evidence

Please find following feedback for the select Committee for the Mental Capacity Act 2005 on behalf of Generate, a charity that supports people with learning disabilities.

To the best of my knowledge, resources for implementing the MCA in terms of training and awareness raising have centred on professionals. I have not come across any government-led training for people who might be subject to the Mental Capacity Act 2005, or the people in their support network. We have seen through circumstances such as Winterbourne that unfortunately professionals cannot always be relied upon to work in accordance to required standards of practice. Rather, people need (to be empowered) to be able to speak up for themselves, their wishes and their rights. In reality this sits at the heart of the Mental Capacity Act 2005. However, what resources have been put into supporting people to understand their rights under this Act? Is it taught in schools? Not just special schools because anyone can become subject to this act at any time in their life? Realistically, how are people supposed to know about their own rights?

Similarly, how are parents and carers supported to understand the Mental Capacity Act 2005 in terms of the rights of the person they care for and their own expectations around involvement in decision making? Parents and carers can be an important advocate for the wishes, rights and best interests of the people they care for. They are also an important source of information and support. Equally, some parents and carers may become frustrated by not being (appropriately or inappropriately) involved in decision making, and this can have far-reaching implications.

Would it be useful to have as an implicit part of preparation for adulthood parents and carers of those young people likely to be subject to the Mental Capacity Act as adults are given information/training/etc about this Act in terms of its implications for the person they care for and their own role in facilitating that person's well-being? And that there was information/training/etc available at the same time for the young people themselves, alongside work to develop individual self-advocacy skills so that they not only know their rights, but have the skills and confidence to challenge those who do not work in accordance with these? Charlton Park Academy is a local special school in Greenwich that is piloting some work around advocacy training for young people. This could be a valuable resource for developing mechanisms for embedding the Mental Capacity Act 2005.

In terms of striking a balance between protection of the carer and protection of the individual lacking capacity, I will share this example from working with a hospital in developing a policy around work with people with learning disabilities. Two policies from two different hospitals. One barely touched on the role of the carer on supporting someone with a learning disability and the importance of involving them subject to the wishes of the individual with a learning disability. The other policy stipulated involvement of a carer at every stage failing to recognise the involvement of the person with a learning disability or that they might have a choice about who is involved in decisions about their care. So not only is the balance not right, the imbalance is itself imbalanced!

There is a broader question that hasn’t been asked. Are the challenges that have been encountered in embedding the Mental Capacity Act 2005 reflective of deficits in the act or implementation plan, or are they reflective of more fundamental barriers that exist within
In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.

society that need to be tackled simultaneously in order for the Mental Capacity Act 2005 to succeed in its aims?

4 July 2013
I will be most grateful if you could bring this to the attention of the Committee. I was involved with the development of the Bill and its passage through the Upper House.98

By way of introduction:

I have been a consultant in Palliative Care Medicine, which is an accredited specialty, and in which I have been a specialty trainer since 1987. I have been responsible for the care of over 25,000 dying and suffering patients in that time from all diagnostic groups, care settings and very many cultures.

My current clinical practice is at Guy's and St Thomas' NHS Foundation Trust, which is part of the Academic Health Sciences Centre known as King's Health Partners, where I work within the local community in inner London as one of the 4 consultant physicians in our interdisciplinary team.

I am also

Professor of Palliative Care in the Cicely Saunders Institute, Department of Palliative Care, Rehabilitation and Public Policy at Kings College London.
Vice president of the Association for Palliative Medicine
Hon Sec to the Committee on Ethical Issues in Medicine, Royal College of Physicians
A collaborative researcher and commentator in Palliative Care and have published over 100 papers.
I take a lead nationally on a variety of projects related to Specialist and Generalist Palliative Care.

My comments relate only to palliative care patients and their families and it have ordered them broadly in line with the questions

98 See Lords Hansard Feb - March 2005 on Mental Capacity Bill

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
1. To what extent has the Mental Capacity Act 2005 (MCA) achieved its aims?

   a. My experience is that the full implications for clinicians at the bedside are not appreciated and that there is a worry on the one hand that one may be in breach of the Law but on the other, that the spirit of what is intended has been overlooked. An example may be the training on DOL seems protean but nothing routine is required in training or support on how to engage with someone whose capacity is fragile, the types of decision that matter and a clear understanding of what may be the requisite capacity in various settings and clinical circumstances. The Code is very helpful, but I feel the place of the Act at the foundation of how we do shared decision-making etc. is weak and would bear much clearer articulation.

   b. Encouragement to everyone responsible for policy documents etc. to refer to the fundamental place the MCA has in all areas of clinical practice would be of great help I feel.

2. Which areas of the Act, if any, require amendment; and how?

   a. Personally, I don’t like the term test for capacity. It implies something factual and medics assume it absent or present. Assessment, evaluation, even measure or some such would be better I think as the obligation to engage with the patient then becomes more likely. With a test, the temptation is to get someone else to “do it” divorced from the contextual issue and what is really the objective – to make sure one is as close to acting in someone’s interests as one may.

   b. There is a link here to my mind with the poverty of communication skills and interpersonal competence in the modern medical workforce that we have seen in Francis and now the LCP Review.

   c. Being clear about the need on the one hand for team working and collective evaluation but on the other, the duties that lay with the senior responsible clinician may help. Clearer balance for the clinician of the weight that is attached to the guidance as compared to the Law may also help.

   d. Areas where capacity may be present according to the criteria, but the person’s capability to make a balanced judgment due say to distress, depression or symptoms may never be codifiable. Some recognition that such dilemmas are real at the bedside and space within legislation to accommodate this type of incapacity/incapability would be most helpful certainly in care of the dying.

   e. The area of advance refusals can be tricky, especially if the current person seems very different from the one who made the decision when capable. Again some more help with situations such as this and what might or might not be legally binding and for what reason. I cover this in some detail elsewhere.

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99 Rob George and Tim Harlow Advance Care Planning: Politically correct, but ethically sound?
In: Advance Care Planning. Thomas K, Lobo B, (Eds) OUP 2009 Chapter 6 55-68
In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
3. Decision Making

a. The decisions of young people below 18 with clear capacity according to the criteria remain disadvantaged when their views vary from their patents / guardians. The examples we see in the young dying of their being subject to traumas because their responsible adults – clinical or social - cannot accept that they are dying remain. It seems very unfair

b. I have always had difficulty with the use of the term best interest as the final formulation and some grand catch-all. It is vulnerable to the Humpty Dumpty approach of “meaning what I say it is”. I would far prefer a term like proper interest. My reasons are as follows:

   i. Everyone coming to the table has interests or else they would not be there. In the real world these are not all directed positively towards the patient. They are their vested interests say in representing their professional opinion, their individual view or explicit personal interest, their budget holding responsibility, bed usage etc. etc. Getting the result they want will be their best interest and there will frequently be some tension with the overall interests of the patient;

   ii. The patient may at some point have expressed a contemporaneous best interest decision, formally or informally, that may now be out of date or inappropriate given their change as a person over time or some unexpected circumstance. Furthermore, even if capable, that best interest may be harmful objectively in fact (e.g. the demand for a futile and potentially life-threatening intervention) or even illegal (eg wanting euthanasia) and therefore, whilst factually from their perspective a personal best interest, is unrealizable or trumped.

   iii. The discussion and formulation of a plan of action is then the negotiated course that flows from the evaluation and balancing of these various interests as they apply to that person at that time – in other words what would be considered the proper interest, all things considered.

   iv. I appreciate that proper interest in this day and age sounds paternalistic, but in the face of the incapable person, as I argued in the reference99, all at the table are being paternalistic, even the former self who projected their contemporaneous view then to a speculative now on behalf of their current self.

   v. I appreciate also that to suggest a change in language is probably pie in the sky, but this is the opportunity to air it. My students find this a much clearer way of understanding and navigating so called best interest meetings or decision making and see that proper interest reflects the consensual way forward when it may not be what the person would have, or currently does within their limitations, consider to be best. The perennial problem of care setting is the most frequent example.
c. The relatively new term Shared decision making is helpful generally and would be one I think should be used for those with limited capacity much as it should apply to young people supra as well, given that in many circumstances the person may be able to contribute to some areas and not others. It keep in mind the view and idea of the presence of the person in the process even if their contribution is very limited.

d. I wonder also if a much more widespread use of IMCAs to help with this should be made clearer. I have had relatively little exposure to them, but I am aware of colleagues who have found their role to be a little ambiguous as to how much executive authority they have.

4. The COP and OPG

a. I have come across too many who have not availed themselves of an LPA because of the cost and processes involved. We have overcome this locally by staying with the spirit of the Act, but I envisage many other clinicians who may not take the same line.

b. Getting IMCAs at short notice to help has also proved difficult and more resource may be needed.

5. the Care Quality Commission and other regulatory bodies

a. I would hope that with Francis, the LCP Review and the new Inspector of Hospitals, that consideration of how best interest decisions are made and how capacity is assessed and recorded with move up the table of evaluating competence and compassion beyond just considering DoLS. I am not competent to comment on the additional powers if any are needed once organizations and clinicians are seen to be accountable for how they treat people and record the basis for their actions.

b. This is a clear place for the role of the professional bodies (ie GMC, NMC, Royal Colleges etc.) in

   i. Increasing the central profile of the MCA as a foundation of clinical care and respect for patients in decision making

   ii. making clear the professional duties of doctors nurses etc. and

   iii. incorporating the understanding and evidence of application of the MCA into elements of revalidation for practitioners regularly involved in care of the vulnerable, dying and incapable.

c. This chimes of course with the Neuberger Report on which I was the Independent

2 September 2013
Gloucestershire MCA Governance Group – Written evidence

Gloucestershire MCA Governance Group – Written evidence

The following response to the House of Lords Select Committee on the MCA 2005 is on behalf of Gloucestershire MCA Governance Group (MCAGG). The authors and contact details are listed at the end of our submission. Our submission has been made directly in relation to the questions posed by the Committee. Where we do not feel we have a useful contribution to make we have stated ‘No response to make’. The submission is based on the following collective experience:

- Strategic engagement in the implementation of the Act since its onset both within the local LIN and its successor the MCA Governance Group (MCAGG)
- A 2012 audit of significant decision mental capacity assessments and best interests decisions across Gloucestershire County Council and our local mental health trust 2getherNHSFT (referred to as the ‘Audit’ throughout the rest of the submission. Available subject to endorsement by local Commissioners on 04.09.13.)
- Introduction of DoLS into Gloucestershire and engagement in the South West MCA/DoLS Implementation Network
- Application of a MCA Gloucestershire multi-agency training strategy including feedback about issues in practice from our independent trainer
- Commissioning of mental health adult social work and AMHP service in Gloucestershire
- Management of IMCA contract for Gloucestershire
- Lead for MCA within 2gether NHSFT.

Overview and context:

1. To what extent has the Mental Capacity Act 2005 (MCA) achieved its aims?

In terms of enabling and empowering people to make decisions for themselves, to plan ahead for a time when they may lack capacity, providing protection for people who lack capacity through a formal decision making framework we believe there has been both limited and patchy progress across different staff groups and providers. Whilst there has been progress in terms of knowledge and awareness of the principles of the MCA there is still a lack of confidence in knowing how to put the principles into practice i.e. the detail of how to carry out a mental capacity assessment and make a best interests decision. This lack of confidence regarding application of the Act in practice can be evidenced by practitioners expressing uncertainly about what questions to ask when undertaking an assessment. We would echo some of the evidence of earlier witness to the Committee that there is more evidence around significant decision assessments than day to day decision-making. Although care planning is named as the relevant documentation to record capacity assessments (Code of Practice 4.61) there is little evidence that suggests this is happening.

2. Which areas of the Act, if any, require amendment; and how?

Overall our view is that the MCA is an excellent piece of legislation with an excellent set of principles. The Code of Practice is widely recognised as providing a clear process and as being easy to understand. It would be helpful however to tighten up the definition of ‘valid and applicable’ in relation to Advance Decisions (ADs) including the creation of a standard form which could include clarity as to detail required for the AD to be valid and applicable.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
As in Scotland it would be helpful if the term 'Mental' was removed and the Act was referred to as the 'Incapacity Act'. The term 'mental' still carries stigma and causes confusion in practice with the MHA. Often practitioners from health and social care organisations struggle to consider the application of the Act as their responsibility and continue to look to mental health services to resolve any capacity issues.

3. At the core of the MCA are its principles and definitions of capacity and best interests. Are these appropriate?

Yes.

Implementation:

4. To what extent have the five principles of the MCA been implemented in frontline practice? What evidence is available to assess this? Is there a satisfactory balance between enablement and protection?

See response to Q1. We find ourselves on a journey between a paternalistic/duty of care approach to a more empowering and enabling approach. Our audit points towards a ‘protection imperative’ often being present in practice, particularly where people find themselves in a hospital setting.

5. How effective was the Government’s implementation plan? What measures were taken to ensure that professionals and families of those who lack capacity know about and act in accordance with the provisions of the MCA? Has it led to sustainable change?

Largely effective through provision of a lot of excellent information particularly the ‘Making decision’ booklets, the core MCA training set, MCA website, SCIE input, regional MCA/DoLS Leads and a ring fenced budget (removal of the latter very unhelpful). However, we believe implementation and audit has been held back by the absence of the provision of national standards forms for assessment/best interests decision-making and advance decisions. Gloucestershire County Council has adopted a standard tool for significant decisions which we understand many other LAs have adopted. In our experience practitioners welcome tools that guide them in implementing the Act in practice.

In terms of families awareness whilst the majority of professional know about the Act in our experience this is not the case for the wider population. We have made efforts to achieve this locally through use of the local press, Carers Gloucestershire (local carers forum) and the provision of a local public information leaflet ‘What is mental capacity and why does it matter’ (attached).

For information our LIN has been superseded by the MCA Governance Group (terms of reference attached) in order to emphasise governance rather than implementation and to engage the local CCG.

6. Is the Act widely known and understood by professionals required to implement it? How does this differ across different sectors, such as health, social care, banking and others?

In our experience there are very different levels of knowledge amongst different professional and settings in the health and social care community. We adopted a multi-agency training
approach (strategy available if required) to try and engage with all sectors. Whilst we recognise the value of e-learning in our experience it is limited in enabling people to develop confidence in the application of the Act. Our local CCG MCA Lead recently commented that 'we need to find a way to improve knowledge and application in primary care – receptionists/nurses/GP's'.

7. Is the Act widely known and understood by those who are directly affected by it and by their non-professional carers? To what extent does the Act provide protection and reassurance for informal carers? Has the right balance between struck between protection of the carer and protection of the individual lacking capacity?

   We have worked with our local carers group to provide information and have given presentations on the Act, but we have limited knowledge around the awareness of this large population group. Our public information leaflet was an attempt to inform, empower and provide reassurance about the Act. We have also developed best interests meeting guidance partly to empower and informal carers about the best interest’s process and to protect individuals lacking capacity.

8. Has the Act ushered in the expected, or any, change in the culture of care?

   See response to Q1 and Q4, a degree of change, but still a lot to be done.

9. Is there any evidence that the provisions of the MCA affect some groups disproportionately? If so, what data exists to compare representation across different socio-economic groups, Black and Minority Ethnic groups, and gender?

   Our local evidence suggests the likelihood of under use by our local BME community rather than any over use. We held a conference for key members of the local BME community about the provisions of the Act. There were very low levels of awareness of the Act. The information was received with great enthusiasm and with a willingness to debate the tricky issues. Our conference concluded that the principles and best interest checklist of the Act provided an excellent vehicle to provide culturally appropriate care.

Decision making:

10. Are those directly affected by the Act being enabled and supported to make decisions for themselves to a greater or lesser extent than they would have been in the past? Does the means by which the decision is made – ‘general authority’, Lasting Power of Attorney, deputyship, Court of Protection – affect the quality of decision making?

   Limited progress regarding people being enabled and supported to make decisions. In some areas this is embedded into practice, in particular health and social care professionals who work with people with learning disabilities. Numerous resources and tools to communicate effectively have been developed in this area. In other areas this concept in not so evident in practitioners thinking and a paternalistic approach continues to be at the fore. In terms of the decision-maker sometimes there are risks of an Attorney not taking account of the principles of the Act and acting within a best interests framework. Noted that the highest standards are set by the Courts.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
11. What evidence is there that advance decisions to refuse treatment are being made and followed?

Our audit demonstrated very limited use of Advance Decisions. We believe this is exacerbated by the absence of standards form.

12. Has the MCA fostered appropriate involvement of carers and families in decision-making?

Yes by setting out in a statutory best interests checklist that carers/families must be involved. There is strong evidence of carer and family involvement from our audit. Clarity about family members not being the decision-maker is not always clearly understood by family members and professionals. This is a particular issue in the transition of young people from Children and Young Person’s services into Adult Services.

13. Has the role of the Independent Mental Capacity Advocate (IMCA) succeeded in providing a voice for clients and an additional safeguard against abuse and exploitation for those who have no-one to speak on their behalf?

Yes, a major success for those who are referred. Locally we have worked to develop qualitative monitoring in order to assure ourselves that the service is fulfilling the function effectively in the absence of feedback from the service user as a result of their limited mental capacity.

14. Has the level of referrals to IMCAs met expectations? What are the reasons for the regional variations in the number of referrals?

Locally we have a relatively high performing IMCA service, but we do not reach DoH targets as set in the IMCA commissioning guidance. We have set a target at 50% of historical activity and the DoH target. Particular areas for improvement in referral rates have been identified in safeguarding, care reviews and SMT decisions from the local acute hospital. In our view credibility of the provider is key to high referral rates.

15. Are IMCAs adequately resourced and skilled to assist in supported or substituted decision making for people lacking capacity?

Currently the service is adequately resourced, but there are significant pressure on costs. In relation to this contract the provider is expected to absorb annual inflation costs. In terms of the skills of IMCAs it would be helpful to have clarity around IMCA CPD requirements.

Deprivation of Liberty Safeguards:

16. Are the safeguards in the Deprivation of Liberty Safeguards (DoLS) adequate?

Whilst applications can be made to the Court of Protection in respect of people who are deprived of their liberty in the community including Supported Accommodation this can be daunting for practitioners. It would be helpful to have an equivalent of the DoLS process for community deprivations of liberty.

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17. Are the processes for authorisation, review and challenge of DoLS sufficiently clear, accessible and timely?

No, it is widely recognised that process not sufficiently clear including accessibility of forms since loss of the DoH DoLS Lead. There is continued uncertainty within Managing Authorities about the process including when and how to refer and this is despite a massive local information campaign.

The Court of Protection and the Office of the Public Guardian:

18. Are the Court of Protection and the Office of the Public Guardian sufficiently understood and accessible to all? Are they operating effectively and successfully?

The Court of Protection is used infrequently. Local guidance has been developed to make the process less daunting. Anecdotally staff report that application to the Court is a slow process.

19. What has been the impact of the introduction of Lasting Powers of Attorney (LPA), especially with regard to decision making on matters of personal care and welfare?

Evidence from our audit and other case file reviews demonstrate very few welfare LPAs are currently in existence. Therefore there is limited impact to date. There is also poor understanding by practitioners that without the decision making authority of an LPA the family are not the decision maker for health and social care decisions.

20. What concerns, if any, are there regarding the costs associated with registering an LPA, or with making an application to the Court of Protection?

Local evidence that this is still viewed as too expensive. ‘Exceptions’ criteria could be clearer and further promoted as this would encourage uptake of people with limited resources. Costs incurred largely as a result of people feeling the need to be supported by a Solicitor.

21. Is legal aid available and sufficient? What impact will the recent and proposed reforms to legal aid have?

No response to make.

Regulation:

22. Is the role of the Care Quality Commission in inspecting on the MCA standards adequate and appropriate? Is there a case for additional powers?

No evidence of any significant impact locally.

23. Should other regulatory bodies, such as health and social care professional regulators, be acting in this area?
We would suggest all health and social care regulatory bodies should set minimum requirements around knowledge and application of the MCA within their registration and approval processes.

Other legislation:

24. How well is the relationship with the mental health system and legislation understood in practice?

Slow improvement but evidence mental health professional including AMHPs are more familiar and feel both they and service users are better protected through use of mental health legislation. The MCA is not always given due consideration in practice by mental health workers who don’t always understand its relation and application in the context of the MHA legislation.

Devolved administrations and international context:

25. Does the implementation of the Mental Capacity Act differ significantly in Wales? No response to make.

26. What lessons, if any, can be learnt from the approaches taken to mental capacity legislation in Scotland and Northern Ireland, or in other jurisdictions? No response to make.

27. Is the MCA compliant with the United Nations Convention on the Rights of Persons with Disability (CRPD)? Are there lessons that can be learnt from the CRPD for the successful implementation of the MCA? No response to make.

29 August 2013
BACKGROUND:

The Gloucestershire LIN was a local multi-agency network set up in 2005 to work across health and social care agencies to ensure implementation of the Mental Capacity Act 2005. This was a national initiative. In 2008 the LIN also became responsible for implementation of the Deprivation of Liberty Safeguards (DOLS) which were introduced through an amendment to the MHA 2007. From that time the LIN took strategic oversight of the MHA 2007.

In April 2012 the MCA and MHA Implementation Manager presented a report to the Gloucestershire Joint commissioning Partnership Executive (JCPE) recommending the replacement of the LIN with a governance forum of MCA Organisational Leads that oversee a governance framework with accountability to the Gloucestershire Health and Well-Being Board (GHWBB). This recommendation was endorsed by the JCPE and discussed in the last meeting of the Gloucestershire LIN on June 11 2012. These terms of reference aim to reflect the decisions of the JCPE, the subsequent period of consultation and September MCAGG.

The MCAGG is no longer responsible for the DoLS which are overseen by the DoLS Joint Management Board and the MHA 2007 which is overseen by the Local Implementation Team (LIT).

MCAGG VISION:

Working in partnership across Gloucestershire health and social care agencies to empower and protect the rights and liberties of Gloucestershire’s most vulnerable citizens through embedding the MCA in day to day practice.

MCAGG OBJECTIVE:

To embed good governance of the MCA in Gloucestershire ensuring good practice and a coherent and consistent approach across organisations within the MCAGG vision.

MCAGG STRATEGIC AIMS:

- To agree strategic priorities for good MCA governance in line with statutory requirements.
- To maintain a multi-agency MCA policy and procedural framework across partner agencies. This includes responsibility for policy review.
- To promote compliance and provide performance information on the MCA in order to achieve full compliance/implementation across all appropriate areas in line with the multi-agency MCA policy.
- To develop, agree and implement good practice guidance and consistent operational processes across partner agencies.

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• To ensure that staff who have responsibility to work within the requirements of the Act fully understand their roles and responsibilities.
• To ensure that good basic information is available for users, families and carers and the public about the Act.
• To contribute to the effective delivery and monitoring of the Independent Mental Capacity Advocacy (IMCA) service incorporating DOLS IMCA and RPR requirements.
• To identify and monitor a multi-agency MCA training and workforce development strategy.
• To ensure that systems are in place to support inter-agency, inter-professional and inter-departmental collaboration where required.
• To work in partnership with others including community organisations and the independent sector.
• To promote relevant quality standards in relation to the MCA, within all partner organisations.
• To meet governance requirements through ensuring Trust Boards/Cabinet or their delegated bodies are kept informed of progress.
• To respond to strategic reviews of MCA implementation.
• To respond to Serious Case Reviews with MCA implications.

MCA ORGANISATIONAL LEADS:

The multi-agency MCA Policy requires MCA Organisational Leads (MCA OLs) for each partner organisation which has endorsed the multi-agency MCA Policy, Procedure and Guidance. They are the named individual responsible for ensuring the quality and efficacy of the services provided to adults who may lack capacity within their Agency. They provide a contact point for other agencies and are responsible for linking into the wider Gloucestershire MCAGG to share information and providing specialist advice to the MCAGG, or where required other agencies in respect of services or information provided by their Agency.

MCA PROFESSIONAL LEADS:

The MCA Policy also requires the identification by MCA OLs of MCA Professional leads in every team/unit who act as local sources of advice and information on the MCA. They are responsible for cascading information about the MCA within their team/unit. They should be someone who has completed the MCA training pathway.

ACCOUNTABILITY:

The Gloucestershire MCAGG is accountable to the Gloucestershire Health and Well-Being Board (GHWWB) via the Joint Commissioning Partnership Executive (JCPE). Copies of annual reports to JCPE will be provided to Gloucestershire Adult Safeguarding Board (GSAB).

FREQUENCY OF MEETINGS:
Meetings of the MCAGG will take place on a quarterly basis.

ADMINISTRATION:
The group will be supported by the DoLS Administrator.

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MEMBERSHIP OF THE MCAGG:

The following core membership consists of MCA OLs from statutory health and social care organisations. Other MCA OLs may be required to attend on an occasional basis for organisation or topic specific agenda items. The Chair will be rotated annually between the MCA OLs for GHNSFT, 2gether NHSFT and Care Services/GCC. The group may also invite other experts or groups to contribute to elements of the work of the group or the working groups on an ad hoc basis.

GCC/Care Services:
(currently Deborah Greig)

Gloucestershire Hospitals NHSFT:
(currently Lynne McEwan)

2gether NHSFT:
(currently Tina Kukstas)

Commissioner/s:
MHA and MCA Implementation Manager
(David Pugh for duration of secondment. A substantive MCA co-ordinating post in the process of discussion)

Joint Commissioner OP and PD
(currently Helen Bown)

Clinical Commissioning Group MCA Lead
(currently Dr Hein Le Roux)

LINks/Health Watch:
(currently Christine Donald)

DoLS Lead:
(currently Theresa Batchelor).

MCA ADVISORY GROUP/NETWORK (attached)

This is made up of former LIN members who are no longer members of the MCAGG and other key MCA stakeholders. The purpose of the group is to maintain a multi-agency channel of communication for discussion and consultation over MCA related issues.

WORKING GROUPS:

The work of the MCAGG will be supported by the establishment of working groups which are accountable to the MCAGG.

REVIEW: Annual. First review September 2013.

Please see link attached.

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In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
1.1 We make this submission to the House of Lords Select Committee on the basis of our expertise in the areas of legal capacity, guardianship, and supported decision-making. Cher Nicholson helped to develop a model of practice for supported decision making while working at the South Australian Office of the Public Advocate (OPA). She has since worked with service providers, advocacy bodies, policymakers, and others in Australia and internationally. Cher recently presented on the OPA Supported Decision-Making Model to Amnesty Ireland and the Centre for Disability Law and Policy, at the National University of Ireland. The OPA Supported Decision-Making Model was independently evaluated, and is being replicated in Canberra and elsewhere, showing similar results. Cher currently works for the Health Community Service Complaints Commission, a rights-based body in South Australia, where she is training disability services and other organisations in the use of Supported Decision-Making practices. Piers Gooding is a PhD candidate at the Faculty of Law, Monash University. His research investigates how supported decision-making might apply in mental health law and policy, as well as capacity-supporting law more generally. Piers is supervised by Professor Bernadette McSherry, Dr Penelope Weller, and Dr Ronli Sifris. He was awarded an Australian Menzies Bicentennial Fellowship to complete six-month research visit to King's College London, where he received provisional supervision from Professor Genevra Richardson.

1.2 The question we seek to address is:

‘What lessons, if any, can be learnt from the approaches taken to mental capacity in legislation in Scotland and Northern Ireland, or in other jurisdictions?’

We refer particularly to lessons that can be learnt from the approaches taken to mental capacity in legislation in two Australian jurisdictions: South Australia and Victoria.

1.3 In order to provide a sense of the legal context, the following should be noted about the nature of adult guardianship law in South Australia and Victoria. South Australia and Victoria have had separate substitute decision-making laws relating to adult guardianship (principally the Guardianship and Administration Act 1993 and the Guardianship and Administration Act 1986, respectively) and involuntary psychiatric treatment and detention (Mental Health Act 2009 and Mental Health Act 1986, respectively) for over two decades. Individuals who are typically subject to guardianship statutes include people with intellectual disabilities, people with cognitive disability (such as dementia and acquired brain injury), and those with psychosocial/mental health disability.

2. Of particular significance to the Select Committee are the practical efforts of the South Australian Office of the Public Advocate to create non-statutory, practical supported decision-making arrangements for people with impaired decision-making. The OPA Supported Decision-Making Model was developed as a deliberate strategy to provide input into guardianship law reform, and to provide supported decision-making even in the absence of a statutory mechanism to do so. 26 participants with significant disabilities joined the pilot project and entered into supported decision-making agreements, though dozens more were included indirectly (as ‘supporters’, service providers, family members, and others). Those who entered agreements invited an informal supporter to sign a contract, which set out the...
guidelines for how the support arrangement would proceed, and a timeline to indicate its duration. The project facilitator helped to establish agreements between the person and his or her nominated supporters, and provided guidance throughout.

2.1 In particular, the pilot of the OPA Supported Decision-Making Model succeeded in diverting people away from both welfare guardianship and administration orders, which are broadly similar to property and affairs deputyships under the Mental Capacity Act 2005 (England and Wales).

2.2 Although the model was initially developed to promote the rights of people with disabilities (PWD) to make their own decisions with whatever support structures they needed, a significant outcome of the pilot was a notable increase in service providers’ appreciation of their clients’ capacity to act. Following client successes in areas that were not initially supported by service providers due to perceptions of incapacity, the service providers realised that the PWD had made an informed decision and recognised the PWD’s responsibility for the decision. In many instances the decision was not seen by the service provider to be in the ‘best interests’ of the person, but service providers were reassured of the person’s enhanced capacity to make the decision.

2.3 Although the pilot was not set up to decrease the number of Administration Orders (which provide for substitute decision-making in financial matters), all who took part in the project and who had these orders were able to demonstrate to the Public Trustee that they were managing their financial affairs. These participants successfully applied to have the administration orders lifted. The participants argued that they were able to use the support model to make their own decisions in all other areas of their lives including matters concerning finances.

2.4 Although the model did not particularly seek to prevent Guardianship, the evaluation found that the model significantly influenced the person’s network of service providers, family and friends to the extent that a Guardianship or Administration Order was never sought. The model being used meant the question of “mental capacity” (in relation to the need to appoint a Guardian/ Administrator) was never raised as a significant issue. The pilot sought to use all of the PWD’s networks of support (including creating new networks if need be), who would then act together as a team. The support network then worked with the PWDs “expressed wish.” While “best Interest” was often raised in discussions, the final say came from the PWD. Those around the PWD accepted that it was his or her right and responsibility to decide.

2.5 In Summary the South Australian model of Supported Decision Making was shown to deliver the following:

- An alternative to Guardianship with a short-term facilitated intervention with long-term benefits.
- A capacity-enhancing method that promotes experiential decision-making with support. (Prior to the pilot, the participants had not had the opportunity to make decisions with the support of a facilitator and a supporter who they had chosen themselves. The decisions often began small and gradually grew into more significant decisions around lifestyle, health, and financial matters—hence, legal capacity was enhanced).
- A way to demonstrate to the Guardianship Board the ability or capacity of the person to make decisions. PWDs could show that Guardianship Orders were unnecessary when support is in place for the PWDs to make their own decisions.
- A way for PWDs to demonstrate their right to make their own decisions to family, friends and service providers.
- A clear process by which services and organisations can apply an alternative support framework to the formal “best interests” arrangements.
- Formalising informal arrangements had the symbolic value of affirming to all parties that the person with the disability was the one who was making decisions, as a peer and an equal. The agreement clarified the roles of the ‘decision-maker’ and the ‘supporter,’ and provided a useful process for negotiating that relationship.
- A way to increase social capital and enhance relationships.
- An inroad to culture change among service providers and others given the starting point of the presumption of capacity, rather than testing for incapacity; the approach begins by looking at ability and what is possible rather than taking a deficit-based approach to assessments and service provision.
- A practical way to normalise the reality that mental capacity fluctuates for the vast majority of the population.
- A practical way to change perceptions about the decision-making ability of PWDs among their social networks, as they see them realising their wishes and preferences.

While the experience of the participants varied considerably, all experienced some benefits from taking part in the pilot program, particularly in relation to health, accommodation and lifestyle matters. The following account of one pilot participant was typical of the group:

Sally was experiencing difficulties when people would not accept that she could make her own decisions with support. At the time, she was 22 years old and had various physical impairments, as well as an intellectual disability. Sally is a wheelchair user. Sally entered the supported decision-making pilot program and chose her mother and sister as ‘supporters,’ both of whom also had intellectual disabilities. Sally’s main ambition was to leave her school and attend TAFE. However, Sally was told to remain at school because there were no services available to support her to use the toilet at TAFE. Her sister and mother supported her expressed wish, knowing this decision might impact on the rest of her life, and sought to provide various options for Sally to consider. They spoke with staff at her school, and asked if they had any suggestions. Eventually, Sally was supported by her family to attend TAFE through a process of problem-solving to overcome the matter of the inaccessible toilet. The supported decision-making arrangement provided a structure for Sally’s decision to be realised. In the end, Sally’s mother and sister also enrolled in TAFE. Together, they attended a class on literacy skills in the mornings, would meet at lunchtime, and would attend their respective courses in the afternoon. This was a significant improvement on Sally’s situation and a good outcome for all involved, which may not have been possible without the structure and facilitation provided by the OPA Supported Decision Making Model. The story also demonstrates the way one decision often leads to another, where growing confidence enables participants to realise their wishes with the knowledge of what is possible.

The major lesson of the pilot program was that PWDs will blossom if they are unconstrained by the judgment of others, and given opportunities to control their own lives.

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2.6 The South Australian Office of the Public Advocate complemented its practical efforts with a number of recommendations for legislative reform. (See D Chartres & J Brayley, ‘Office of the Public Advocate South Australia Submission to the Productivity Commission Inquiry into Disability Care and Support’ August 2010: 27 http://www.pc.gov.au/__data/assets/pdf_file/0012/101442/sub0325.pdf accessed 19 July 2013). The model as it stands, while not statutory, was able to provide agreements which were influential in assisting PWDs to express their will and preferences, and to have their decisions realised. The pilot indicated that if support arrangements became statutory agreements, they may work even more effectively.

3. Further lessons can be gained from Victorian guardianship law reform activity in recent years. A key driver of the reform process is the need to align adult capacity laws in Australia with the CRPD’s mandate to support people with disabilities to exercise their legal capacity. The reform process has been tailored towards Article 12 of the CRPD in particular.

3.1 Under the current legislation, six broad appointments for substituted decision-making are available. Victorian guardianship law does not currently provide any formal avenue for supported decision-making.

3.2 However, a recent and comprehensive report by the Victorian Law Reform Commission (VLRC) (2012) that draws broadly on Canadian adult guardianship law, recommends the introduction of two statutory mechanisms for supported decision-making into current adult capacity law: ‘supporters’ and ‘co-decision making’. (Similar law reform measures were advanced in the Irish Assisted Decision-making Bill). The mechanism for ‘supporters’ would see the statutory recognition of informal supporters to assist some people with the process of gathering information, making important decisions about their lives, and implementing those decisions. The VLRC saw supported decision-making appointments and orders as useful for both personal and financial decisions. The statutory mechanism for ‘co-decision-making’ would see the appointment of a ‘co-decision maker’ who would make decisions jointly with the person requiring support. This mechanism would be closer in kind to substitute decision-making, given that the individual requiring support could not make certain decisions on his or her own without the agreement of the co-decision-maker. However, this differs from the appointment of a guardian or an administrator who uses strict substitute decision-making rather than making decisions jointly.

3.3 The introduction of these additional measures would see the creation of a ‘stepped up’ model for adult assisted decision-making laws. This spectrum would see, at one end, autonomous decision-making and non-intervention by the state, and at the other end, substitute decision-making and extreme state intervention. In between these two extremities would be a range of options, including supported- and co-decision-making arrangements.

3.4 Where substitute decision-making measures are taken, the VLRC suggests that ‘the principle of “substituted judgment” should have greater prominence in new guardianship laws.’ Substituted judgment refers to prioritising the supported persons wishes and preferences. The VLRC was flexible on this point and acknowledged that substituted judgment would not always be appropriate, making recommendations for alternative guiding principles in certain circumstances.
circumstances (for example, where a supporter is making investment choices for a person who has no financial experience or no direct interest in a financial decision pertaining to him or her, substituted judgment appears inappropriate). Instead, according to the VLRC, guidance could be sought using the overarching goal of ‘promoting the personal and social wellbeing’ of the supported person. As such, when making financial decisions, the VLRC proposes that ‘financial decision makers should be required to apply the prudent person principle in managing a person’s finances to the extent this promotes their personal and social wellbeing’—which itself takes account of a person’s will and preferences). In contrast to ‘substituted judgment,’ the VLRC accepted criticism of the ‘best interests’ principle as being too vague, and for being used as a euphemism for overriding the will of the individual. Practical guidance on the application of substituted judgment can be found in South Australia, where the Guardianship and Administration Act (1993) (SA) uses substituted judgment as the paramount consideration in the duties of substitute decision-makers.

3.5 Also of note, is the VLRC proposal for greater ‘overlap’ between mental health and guardianship laws. Its major recommendation in this regard is to authorise enduring personal guardians to make psychiatric treatment decisions over and above the power of psychiatrists to make treatment decisions under the Mental Health Act 1986, if the person subject to the guardianship order is deemed an involuntary patient due to considerations of his or her own wellbeing—though not for reasons of public safety. The VLRC emphasises the view that guardianship powers should only be used for the benefit of the represented person and not for the protection of the public. At a minimum, this substituted decision-making measure would ensure that the person who is subject to civil commitment powers is potentially able to appoint a proxy in advance, instead of having the ‘clinical guardianship’ granted to a psychiatrist by default.

3.6 A supported decision-making pilot is currently underway in Victoria, headed by the Victorian Office of the Public Advocate. The pilot appears to be modelled broadly on the South Australian Supported Decision-Making Model, though it takes specific guidance from the proposal of the VLRC’s 2012 report on guardianship. The pilot will seemingly have a greater focus on providing support to people with impaired decision-making capacity who are significantly socially isolated and for whom volunteer supporters from the general community might be trained and appointed. The Office of the Public Advocate in Victoria has worked in close consultation with its counterpart in South Australia in the development of the Victorian supported decision-making pilot, which is in its very early stages of implementation.

4. In conclusion, some Australian States and Territories are engaged in law reform endeavours that aim to move adult capacity laws beyond substituted decision-making based on an unrealistic capacity/incapacity binary. Law reformers in South Australia and Victoria are exploring alternatives in guardianship law and policy that are more in line with Article 12 of the CRPD. Initial efforts, particularly in South Australia, are providing evidence of practical success. England and Wales could draw from Australian efforts to create more statutory mechanisms for supported decision-making, and to establish pilot programs, which can be evaluated to inform policy change.

31 August 2013.
Dr Helen Greener, Professor Julian Hughes, Professor John Bond, Dr Stephen J. Louw, Marie Poole, Professor Louise Robinson and Charlotte Emmett – Written evidence

Dr Helen Greener, Professor Julian Hughes, Professor John Bond, Dr Stephen J. Louw, Marie Poole, Professor Louise Robinson and Charlotte Emmett – Written evidence

Submission to be found under Professor Julian Hughes.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Hampshire County Council – Written evidence

Hampshire County Council – Written evidence

1. To what extent has the Mental Capacity Act 2005 (MCA) achieved its aims?

The MCA has created a useable framework for assessing a person’s mental capacity and intervening when necessary in a person’s best interests. However it does not seem that there has been an equivalent focus or progress relating to the other aim of the MCA – to support vulnerable persons to make their own decisions and to make future arrangements for decision making. We do not see great use of Advance Decisions to Refuse Treatment (ADRT) or Health and Welfare Lasting Power of Attorney (LPA) by people and greater efforts need to be made to promote these and make them accessible.

2. Which areas of the Act, if any, require amendment; and how?

Generally more emphasis needs to be placed on supporting vulnerable people to make their own decisions, promoting principles in ‘Independence, choice and risk: a guide to best practice in supported decision making’.

3. At the core of the MCA are its principles and definitions of capacity and best interests. Are these appropriate?

The principles act as a useful training tool for staff and a useful starting point for the MCA. The definition of the assessment of capacity is very useful and forms the basis of the assessment Toolkit used by our social care staff. However, a review of and more detailed guidance on carrying out capacity assessments would be helpful, in particular the importance of relevant information for specific decisions, including assisting a person to understand relevant information.

Implementation

4. To what extent have the five principles of the MCA been implemented in frontline practice? What evidence is available to assess this? Is there a satisfactory balance between enablement and protection?

Clearer guidance regarding best interests may be helpful if this could emphasise elements such as the wishes of the individual and how their emotional needs should be considered relative to risks and safety.

There needs to be better understanding of the need to apply these principles in all settings including the person’s own home and schools and colleges and to all levels of decision making, not just major decisions and not just in situations when there are disputes or where a person is not accepting care that is offered to them.

5. How effective was the Government’s implementation plan? What measures were taken to ensure that professionals and families of those who lack capacity know about and act in accordance with the provisions of the MCA? Has it led to sustainable change?

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
The emphasis in the implementation plan on local authorities rolling out this legislation has led to a fairly widely held belief that mental capacity is a local authority role and that only social workers should complete assessments of capacity as well as to a slower adoption of the Act in hospital settings. Greater awareness raising amongst members of the public as to the relevance of the MCA and responsibility for decision making would be helpful. We suggest that consideration might be given to introducing a specific requirement that best interests decisions made by the local authority or professional decision maker should be in writing to add clarity. This may be particularly useful in situations of fluctuating capacity where decisions need to be taken at particular points in time.

6. Is the Act widely known and understood by professionals required to implement it? How does this differ across different sectors, such as health, social care, banking and others?

There is a superficial awareness of the Act but understanding of the principles and usage of the Act is very variable.

Implementation of the Act in health settings has been slower than in social care as described above.

There have been reports of Police and Ambulance colleagues being reluctant to operate under section 5 of the MCA (best interests) as this is considered to be a defence for actions taken but not an explicit power or duty. This causes ongoing difficulties when trying to arrange transport for people who need treatment but are not compliant due to their illness or mental disorder.

7. Is the Act widely known and understood by those who are directly affected by it and by their non-professional carers? To what extent does the Act provide protection and reassurance for informal carers? Has the right balance between protection of the carer and protection of the individual lacking capacity?

Awareness of the Act by carers is likely to be varied and there may be a conflict of interest between the person’s best interests and the wishes of the carer.

8. Has the Act ushered in the expected, or any, change in the culture of care?

The MCA has led to a greater awareness of the Human Rights Act, the role of ‘family and private life’ in making decisions on behalf of vulnerable individuals (because of its citing in caselaw) and supports efforts to develop positive risk taking approaches in social care. The requirement to consult with family members / interested parties when determining best interests has made decision making more transparent and open. Best interests and DoLS are developing a clearer awareness that when we act we must be aware of the legal framework under which we are operating.

9. Is there any evidence that the provisions of the MCA affect some groups disproportionately? If so, what data exists to compare representation across different socio-economic groups, Black and Minority Ethnic groups, and gender?

Evidence from the monitoring of referrals to IMCA services and referrals for DoLS Authorisations would suggest that there are high levels of activity relating to older women in care services. This may be due to a lack of other legal frameworks to safeguard this group, in order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
however it does suggest that younger persons, adults with mental health problems and people from BME backgrounds are not represented in the use of MCA. There may be a number of reasons including the difference in life expectancy between men and women, younger adults being within a hospital or living in non-registered settings.

Decision making

10. Are those directly affected by the Act being enabled and supported to make decisions for themselves to a greater or lesser extent than they would have been in the past? Does the means by which the decision is made – ‘general authority’, Lasting Power of Attorney, deputyship, Court of Protection – affect the quality of decision making?

The provisions for assessing capacity and making best interests decisions have had greater prominence than the provisions for supporting individuals to make their own decisions or make advanced arrangements such as LPAs or ADRTs. Greater focus on this aspect of the Act is required. It is the knowledge and expertise of the decision maker rather than the means that affects the quality of decision making.

11. What evidence is there that advance decisions to refuse treatment are being made and followed?

There is limited evidence for the use of ADRTs or for public awareness of what they are or how they may be used. The judgement in A LA v E (2012) may further undermine confidence in ADRTs if the suggestion is that a formal assessment of capacity is required at the time of drafting to validate it.

12. Has the MCA fostered appropriate involvement of carers and families in decision-making?

Yes. In particular there is a greater focus on attempting to resolve disputes with family members who have differing views from Adult Services regarding best interests of a vulnerable person. This has been promoted by the knowledge that should a significant dispute remain unresolvable it requires referral to the Court of Protection for a judicial decision.

13. Has the role of the Independent Mental Capacity Advocate (IMCA) succeeded in providing a voice for clients and an additional safeguard against abuse and exploitation for those who have no-one to speak on their behalf?

Our experience is that IMCAs have proved to be a valuable addition to the support available to vulnerable persons at significant points in their lives.

The availability of IMCA for persons subject to safeguarding procedures has been especially beneficial in situations where there are known family members but they are not in a position to advocate for the person. Currently it is discretionary for local authorities to offer this IMCA service; consideration should be given to ensuring that it is available if required nationwide.

14. Has the level of referrals to IMCAs met expectations? What are the reasons for the regional variations in the number of referrals?

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Referrals steadily increased in the first four years of the implementation of the MCA but locally they have remained static over the past two years, against our expectations.

Serious medical treatment referrals have remained at a very low level with certain pockets of activity (such as individual community dentists) but poor use of IMCA in acute hospitals for treatment, though greater use for hospital discharge situations.

The use of section 39D IMCAs in DoLS cases has remained lower than the expectations placed upon us by the Department of Health but our experience locally is that when offered this service, Representatives decline it as the offer is made at the wrong time. Automatic referral for s39D IMCAs would not be meaningful as they would not be offering support when families want it. More helpful would be the offering of readily available support when requested.

15. Are IMCAs adequately resourced and skilled to assist in supported or substituted decision making for people lacking capacity?

Yes and we have now recommissioned these services to reflect our better understanding of them. In Hampshire we have combined this with DoLS Paid Representative (RPR), IMHA and Mental Health Advocacy to improve management of the schemes, share management costs and improve links between these advocacy schemes that previously acted in isolation. The Advocacy qualifications for IMCAs have proved valuable and the quality of advocates has been high.

Deprivation of Liberty Safeguards

16. Are the safeguards in the Deprivation of Liberty Safeguards (DoLS) adequate?

No. Access to DoLS is too dependant upon the Managing Authority recognising that a referral should be made and identifying deprivation of liberty when it occurs. Once a manager has referred once and we can support them with understanding the process they are more likely to refer again. This learning is less likely to be effective in hospitals due to the high number and turnover of staff.

Referrals are still often only made when someone physically attempts to leave the premises and not enough attention is paid to the person’s objection to accommodation or treatment.

The most useful safeguard is the assessment and authorisation process itself which offers a degree of scrutiny to complex care situations and offers an independent view. We use conditions to try to resolve unsatisfactory situations and the assessment process also identifies situations that require safeguarding actions, review of best interest decisions or application to court for determination of best interests.

We would also suggest that consideration is given to the language used in Sch A1 and 1A to better align with the approach in the rest of the MCA.

17. Are the processes for authorisation, review and challenge of DoLS sufficiently clear, accessible and timely?

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
The other significant safeguard is access to the Court of Protection which is an intimidating and complex process. A more accessible method of initial challenge in respect of DoLS, such as a tribunal system that could operate more quickly and locally, with appropriate support to a Personal Representative/greater use of advocates, would be an improvement and make the safeguards more meaningful.

Automatic review of standard authorisations and conditions together with involving the commissioner of care would streamline the process and reduce the confusion of managing authorities. Additionally, we would support the ability to issue proceedings regionally, rather than having to specifically request a transfer to a region.

The Court of Protection and the Office of the Public Guardian

18. Are the Court of Protection and the Office of the Public Guardian sufficiently understood and accessible to all? Are they operating effectively and successfully?

Our experience is that the Court (COP) and Office of the Public Guardian (OPG) are often misunderstood. When attempting to contact them from a corporate deputy perspective, often there will be significant delay, and when contact is successful, the OPG staff will redirect the caller to the Court and vice versa. When the Court has appointed HCC as deputy, often it will send little explanatory information as to why it may have displaced an attorney or private deputy and then attempt to charge HCC for associated information to enable us to take on the corporate role. HCC’s experience generally in relation to the OPG and COP helplines are that they remain unanswered, although responses to email enquiries are picked up within two to three days. Often COP20A’s are mislaid by the Court and case officers need to chase and often need to send scanned copies. Consideration should be given to ensuring the forms are user friendly and concise.

19. What has been the impact of the introduction of Lasting Powers of Attorney (LPA), especially with regard to decision making on matters of personal care and welfare?

20. What concerns, if any, are there regarding the costs associated with registering an LPA, or with making an application to the Court of Protection?

The costs for deputyship application are the same regardless of the complexity. This may be something to consider, as OPG rate the complexity and set charges accordingly. The cost of application to Court of Protection may be prohibitive in absence of legal aid. A local Tribunal system may be more cost effective and less intimidating.

21. Is legal aid available and sufficient? What impact will the recent and proposed reforms to legal aid have? Consideration should be given to the person affected being automatically entitled to non-means tested legal aid to ensure appropriate representation.

Regulation

22. Is the role of the Care Quality Commission in inspecting on the MCA standards adequate and appropriate? Is there a case for additional powers?

It is important that in monitoring the use of the MCA there is not an undue focus on merely counting assessments of capacity completed, as this could reinforce the perception of mental
capacity assessments as stand alone formalised activities and reduce the emphasis on using the MCA as an integral part of supporting vulnerable people in all activities and decisions, no matter how small. Inspection is better used if ensuring that the appropriate systems, guidance and training are in place in all organisations, both providers and commissioners of care.

23. Should other regulatory bodies, such as health and social care professional regulators, be acting in this area?

HCPC and NMC codes of conduct already require practitioners to be aware of the legislation regarding Mental Capacity. Greater priority could be given to this to underline the importance of this legislation.

Other legislation

24. How well is the relationship with the mental health system and legislation understood in practice?

Devolved administrations and international context

25. Does the implementation of the Mental Capacity Act differ significantly in Wales?

26. What lessons, if any, can be learnt from the approaches taken to mental capacity legislation in Scotland and Northern Ireland, or in other jurisdictions?

27. Is the MCA compliant with the United Nations Convention on the Rights of Persons with Disability (CRPD)? Are there lessons that can be learnt from the CRPD for the successful implementation of the MCA?

30 August 2013
As a GP with over 25 years' experience, I have serious reservations about the Mental Capacity Act and its use in practice. Indeed, I seriously suggest that, in its present form, it would be safer to delete it from the statute book and re-draft it.

Unlike the Mental Health Act which asks us to answer 2 simple medical questions when sectioning a patient, which can be answered in medical language, the Mental Capacity Act is a legal document which is written entirely in legal language, and is thus, in its own right, a barrier to medical assessment in the Community.

An assessment of a patient's mental capacity prior to this Act was part of the medical examination process with the patient's appearance, speech, behaviour etc all adding up to a medical judgement as to the best way of managing a case; to make assessment of capacity a separate issue and, in particular, couching this in non-medical language, is potentially asking for serious consequences. Indeed there is a case reported by Birmingham and Solihull Mental Health Trust (STEIS ref 2013/132) where the patient died, potentially because of this confusion (instead of making an assessment of the case in medical terms alone and acting accordingly, it would appear that making a separate assessment of capacity confused several ambulance crews such that the patient was not taken to hospital before it was too late).

To assist in dealing with emergency situations, the Act needs to be re-drafted so that it asks questions in medical language which can be understood and worked into a medical assessment, in the sometimes difficult social conditions in which this needs to be done; to switch out of medical terminology and thought, into legal language, is disruptive to medical assessment and is liable to cause confusion. I write this in my Safeguarding capacity as well, as I believe that this Act is, in its current form, a threat to public safety.

2 September 2013
We have recently conducted research into the experience of carers of people living with dementia from socio-legal and social psychological perspectives. The ‘Duties to care’ project was interested in the experiences of carers of people with dementia in accessing health and social care services.

The project research questions were:

- What do carers of people with dementia think about the regulation of care services?
- How effective are the legal frameworks surrounding dementia care from carers’ perspectives?
- What are the key issues and concerns that carers have in relation to accessing health and social care support services?

The research included two empirical components with carers of people living with dementia: a survey (185 responses) and four focus groups with 15 participants. Our responses to the questions from the Select Committee draw on our research in this area, and as such we have not addressed the questions posed by the call for evidence directly. We have appended copies of the newsletters that we have prepared for participants in our research and other stakeholders. These newsletters provide a summary of the findings from the research in lay terms. We have also enclosed copies of academic articles (published and in press) that draw on findings from this research project for your information. We would be happy to provide further information about our findings and to give oral evidence to the committee if this would be helpful.

In considering whether the MCA has achieved its aims, it is important to be clear about which aims are being addressed, given there are a variety of different aims embedded in the legislation. We have identified the following as aims within the MCA:

1. To confirm in law a presumption of full legal capacity
2. To ensure people are given all appropriate help and support to make their own decisions or maximise their participation in decision-making processes
3. To ensure that any decision made or action taken on behalf of a person who “lacks the capacity to make the decision for or act for themselves is made in their best interests”
4. To strike the appropriate balance between the right to make decisions and to be protected from harm
5. To ensure that where decisions are made or actions are taken “for or on behalf of a person who lacks capacity” these decisions or actions must be in the person’s best interests.

100 The ‘Duties to Care: Socio-Legal Explorations of Caring for People with Dementia’ project was funded by the British Academy (Small Grant SG100017).

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.

The extent to which these aims have been achieved is largely a matter for evidence from practice, rather than academic or legal commentary. In so far as legal analysis is concerned, it appears that the developing jurisprudence of the Court of Protection has begun to acknowledge the nuances of capacity as understood within the MCA. Yet phrases like “her present beliefs are not based in reality”\textsuperscript{101} continue to be used to describe and invalidate views expressed by people living with dementia, despite the undermining negative connotations of such approaches to constructing the views and perspectives of people living with dementia (Harding, 2012). Arguably, failing to consider the views of people with impairments that may affect their capacity goes against both the spirit and letter of the MCA. As such, the extent to which the MCA has ushered in a change in understandings of people with limited mental capacity remains open to question.

Perhaps the most controversial part of the MCA has been the impact of the Deprivation of Liberty Safeguards (DoLS). The DoLS provisions appear to have provided more confusion than clarification to many people working in the care sector. The rules are complex, confusing and hard for lay people to understand. The need for DoLS is clear, but given the importance of them, legislative amendment may enable clearer principles to be put in place to ensure better understanding. Participants in our research projects did not appear to have clear understandings of the requirements of the current DoLS, nor of where these would be relevant. This suggests that clearer information should be made available to the public about what the DoLS rules are, and how they apply to people with dementia and their carers.

The definition of capacity under the MCA currently requires that the person making a decision must be able to understand, retain, use or weigh information relating to a decision and that s/he must be able to communicate a decision. It is likely that the current definition of capacity is incompatible with Article 12(2) of the United Nations Convention on the Rights of People with Disabilities (CRPD), which states that: “States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life”. This suggests that legal capacity should not be dependent on mental capacity. The CRPD also calls into question the validity of the ‘best interests’ substituted decision-making framework under the MCA. The CRPD suggests that ‘best interests’ should not be used to over-rule decisions that are made by people with mental capacity-limiting disabilities. The requirement to use and weigh information is particularly problematic in this area, as it can be constructed as demanding evidence of a higher decision-making standard than is imposed on those without such disabilities (Harding, 2012). Some have interpreted the MCA’s ‘best interests’ framework as being able to overrule decisions made (whether or not the person making that decision has capacity to make it) on the grounds of ‘best interests’. This is sometimes referred to as an ‘objective’ account of best interests, rather than a ‘subjective’ account of best interests. Such an interpretation is likely to be incompatible with the ethos and letter of the CRPD, and it may be necessary to clarify the limitations on best interests decision making whilst still ensuring that vulnerable adults can be protected from harm.

Our empirical research with carers of people with dementia (Harding, 2014) suggests that different relational contexts between carers and people with dementia have an impact on whether health and social care services providers: are sensitive to the needs of the carer;

\textsuperscript{101} Dorset County Council v EH [2009] EWHC 784 at [101]
take carers’ needs into consideration when assessing service or healthcare needs of a person living with dementia; or consult carers about significant health care decisions. Cohabiting and spousal care relationships appear much more readily understood, more consistently recognised by health and social care professionals, and therefore are better supported than other types of caring relationship. As such, more work may need to be done to ensure effective implementation across the full range of diverse caring relationships.

In our recent empirical research project with carers of people living with dementia (Harding & Peel, 2010), carers of people living with dementia were asked a number of questions about Power of Attorney and decision-making. Five questions relating to Power of Attorney (PoA) status were asked in the questionnaire. Of these respondents, nearly two thirds, 63.8% (n = 118) held financial PoA, and 34.1% (n=63) did not. Far fewer respondents held welfare PoA, with just one third (n= 60, 32.4%) reporting that they did have a welfare PoA, and 100 respondents (n=54%) reporting that they did not. 18 respondents (9.7%) answered “don’t know” to this question, and 7 (3.8%) did not answer. A further 18 respondents (9.7%) reported having been appointed as a Deputy for the person the carer for. Of those who reported holding a welfare PoA, several (n=12, 20% of those claiming to have a welfare PoA) suggested that this had been registered prior to 2007, and therefore prior to the date that the relevant legislation came into force. There was, therefore, a degree of confusion about both the welfare PoA and the status of Deputy, suggesting that many carers would benefit from further (or clearer) information about the differences between various types of legal authorisation to make decisions on behalf of the person they care for. Just under half of our research participants (n=89, 48%) had consulted a solicitor for advice about legal aspects of providing care and financial planning in relation to dementia. In focus group discussions, it became apparent that participants found accessing legal advice difficult because either it was hard to find local solicitors who had appropriate expertise in mental capacity issues, or because access to quality legal advice was too expensive (Harding & Peel, 2012).

The research that we have carried out to date with people living with dementia has not specifically evaluated the Independent Mental Capacity Advocate (IMCA) regime, nor individuals' experiences of mental capacity advocacy. One key finding from our research project, however, is that many familial carers of people living with dementia find the ‘system’ confusing and difficult to navigate (Peel & Harding, 2013). Carers report that they often find navigating the system more difficult than the experience of caring for a person with dementia, and many suggested that having access to a single point of contact that assisted them in finding appropriate support services would be helpful. There may, therefore be a need for an expanded advocacy role, supporting those people with impaired mental capacity who do have familial carers as well as those who do not.

Finally, we note that the sections of the MCA that govern research (ss. 30-34) may unduly restrict participation in social science research projects that would improve understandings of the experience of living with a condition that impacts on mental capacity, though may not directly influence care or treatment, or provide a direct benefit to the participant. Of particular concern are the provisions that may require withdrawal from a research project that a person with dementia has previously given valid consent to, on the recommendation of a carer or other person who has been consulted by the research team, even though the research participant themselves has said or done nothing that indicates he or she would prefer to withdraw. This requirement may make longitudinal research that involves experiences of ageing, and/or people living with dementia (for example) particularly difficult.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
We hope that the findings from our research, whilst not directly focused on reviewing the Mental Capacity Act 2005, will be of use to the committee in their review. Please do not hesitate to get in touch if you require further information.

Enclosed documents:

Peel, E. & Harding, R. (2013) “It’s a huge maze, the system, it’s a terrible maze”: Dementia carers’ constructions of navigating health and social care services. *Dementia: The International Journal of Social Research and Practice*. Advance access. doi: 10.1177/1471301213480514

2 September 2013
Haven Lincoln Crisis House – Written evidence

**Overview and Context**

To what extent has the Mental Capacity Act 2005 (MCA) achieved its aims?

Totally in our sector of care .. mental health Crisis House

Which areas of the Act, if any, require amendment and how?

None

At the core of the MCA are its principles and definitions of capacity and best interests. Are these appropriate?

Yes, totally

**Implementation**

To what extent have the five principles of the MCA been implemented in frontline practice? What evidence is available to assess this? Is there a satisfactory balance between enablement and protection?

All our clients in crisis house service are empowered to be part of the decision making process regarding their treatment and ongoing support from mental health services

How effective was the Government’s implementation plan? What measures were taken to ensure that professionals and families of those who lack capacity know about and act in accordance with the provisions of the MCA? Has it led to sustainable change?

Training and information packs have been widely available and staff within our service provided with training on mental Capacity Act and its contents/aims.

Is the Act widely known and understood by professionals required to implement it? How does this differ across different sectors, such as health, social care, banking and others?

Yes, as far as our experience with services in Lincolnshire are concerned

Is the Act widely known and understood by those who are directly affected by it and by their non-professional carers? To what extent does the Act provide protection and reassurance for informal carers? Has the right balance between struck between protection of the carer and protection of the individual lacking capacity?

From our experience of working with service users and their carers, we believe that people have a good working knowledge of the Act.

Has the Act ushered in the expected, or any, change in the culture of care?

Our service users feel more able to have their say in their care and take ownership of their diagnosis and associated issues

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Is there any evidence that the provisions of the MCA affect some groups disproportionately? If so, what data exists to compare representation across different socio-economic groups, Black and Minority Ethnic groups, and gender?

This would be impossible for us to comment on in our sector of care in Lincolnshire as our service users are predominantly from white European communities.

**Decision Making**

Are those directly affected by the Act being enabled and supported to make decisions for themselves to a greater or lesser extent than they would have been in the past? Does the means by which the decision is made – ‘general authority’, Lasting Power of Attorney, deputyship, Court of Protection – affect the quality of decision making?

Service users are definitely being encouraged and supported to make decisions for themselves more and more with the recent growth in service users groups and forums around the county.

What evidence is there that advance decisions to refuse treatment are being made and followed?

Am unable to comment on this

Has the MCA fostered appropriate involvement of carers and families in decision-making?

Yes

Has the role of the Independent Mental Capacity Advocate (IMCA) succeeded in providing a voice for clients and an additional safeguard against abuse and exploitation for those who have no-one to speak on their behalf?

Yes

Has the level of referrals to IMCAs met expectations? What are the reasons for the regional variations in the number of referrals?

Can't comment on this

Are IMCAs adequately resourced and skilled to assist in supported or substituted decision making for people lacking capacity?

Yes but I can only comment on people receiving services in Lincolnshire

Deprivation of Liberty Safeguards

Are the safeguards in the Deprivation of Liberty Safeguards (DoLS) adequate?

Yes
Haven Lincoln Crisis House – Written evidence

Are the processes for authorisation, review and challenge of DoLS sufficiently clear, accessible and timely?

Yes

The Court of Protection and Office of Public Guardian

Are the Court of Protection and the Office of the Public Guardian sufficiently understood and accessible to all? Are they operating effectively and successfully?

They appear to be understood and accessible to all and from our experience are effective

What has been the impact of the introduction of Lasting Powers of Attorney (LPA), especially with regard to decision making on matters of personal care and welfare?

Can’t comment on this

What concerns, if any, are there regarding the costs associated with registering an LPA, or with making an application to the Court of Protection?

None that we have been made aware of

Is legal aid available and sufficient? What impact will the recent and proposed reforms to legal aid have?

Can’t comment on this

Regulation

Is the role of the Care Quality Commission in inspecting on the MCA standards adequate and appropriate? Is there a case for additional powers?

It is appropriate and we don’t believe it needs additional powers in the crisis house support sector that we are involved in

Should other regulatory bodies, such as health and social care professional regulators, be acting in this area?

No, there’s no need at present

Other Legislation

How well is the relationship with the mental health system and legislation understood in practice?

Good

Devolved administrations and international context

Does the implementation of the Mental Capacity Act differ significantly in Wales?

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
What lessons, if any, can be learnt from the approaches taken to mental capacity legislation in Scotland and Northern Ireland, or in other jurisdictions?

Is the MCA compliant with the United Nations Convention on the Rights of Persons with Disability (CRPD)? Are there lessons that can be learnt from the CRPD for the successful implementation of the MCA?

11 August 2013

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.

Submission to be found under Victoria Butler-Cole.
Head First – Written evidence

I am writing to respectfully provide information to the House of Lords Committee that is presently looking into the issue of the workings of the Mental Capacity Act (2005) in practice.

I am Jo Clark-Wilson, Managing Director of Head First, an independent company, which has been providing case management and care for severely brain-injured adults over the past twenty years.

Overview

I have significant concerns with the implementation of the Act, with particular reference to individuals with an acquired brain injury, especially in respect of:

1. Those brain injured clients, who have a lack of insight or fluctuating insight and are able to logically say what they should do but are unable to apply this into practice.

2. Poor working practices in preparation of capacity assessments –

   • Social Workers in statutory services, who undertake assessments but have no knowledge of the ‘invisible deficits’ after brain injury and take everything from clients at ‘face value’ without liaising with others who have knowledge and experience of caring for or working with them (i.e. family members or other professionals).

   • Social Workers in statutory services, who do not take account of the client’s behavioural patterns relating to the capacity question (i.e. taking the ‘here and now’ of what clients say they will do rather than what they do).

   • Social Workers in statutory services (from experience of working with clients in four different geographical areas), who override the outcomes of capacity assessments prepared by independent clinical specialists in brain injury. They have stated, in their view, the client has capacity and this is valid, as their assessment has been prepared more recently.

3. The use of “Capacity” as a way of statutory services avoiding the need to provide any form of service and input.

4. The use of IMCA’s, who are also not aware of the ‘invisible deficits’ after brain injury.

5. The time-consuming and costly processes associated with challenges to Capacity/Best Interests.

Of most concern are the increased risks and vulnerability for severely brain-injured clients and their families, as a consequence of the above.

Our experience as an organisation that works over the longer-term with people with complex needs following an acquired brain injury is that the lack of condition-specific
knowledge and experience by statutory staff, can sometimes make the Act a handicap to the well-being of brain-injured people. In particular there are serious issues with the assessment of brain-injured clients who have an intellectual awareness of their condition but do not have insight into it. These are the clients who sound competent and able, particularly in a structured or semi-structured assessment but fail to use their own knowledge and carry out their stated intentions in practice, because they cannot. This is a function of their condition but misunderstood by those who lack brain injury specific experience and knowledge.

**Specific examples**

Our organisation has had 6 separate instances over the last three years where issues of Capacity and Best Interests decision-making has given rise to significant concerns.

On each and every occasion the core issue, the fundamental problem that has lead to difficulties, has been the assessment of capacity by staff lacking knowledge and experience of working in the field of brain injury (such as local authority Social Workers or non-specialised doctors). Sadly these assessments have often been undertaken by staff who visit once, take a “snap-shot” view, do not speak to third parties and take a contrary position to knowledgeable family members and the skilled and experienced clinicians who may have been working with the brain injured party for many years. It is clear from the capacity assessments and decisions taken that knowledge of cognitive and executive functioning is not incorporated into the assessment and that the difference between intellectual awareness and insight is not understood. It is also evident that capacity assessors, by the nature of their questions, have led the client into saying what they have wanted to hear. Therefore, what is assessed is simply what is said (more accurately what is supported to be said), not what is done, or will or will not be done in the future.

In a semi-structured interview many of the people we work with will be able to sound wholly competent and be very plausible. Knowledge of acquired brain injury and the loss of insight would lead one to understand that third party corroborative evidence is required, as is observation over time, and far less emphasis given to simply how an individual presents and what they say, untested against reality.

In order to highlight the issues, common to the many of our clients, one case study is described. One young man we work with cannot generate ideas. This means that he cannot independently problem solve, as he has no ideas to weigh up and consider between. He looks entirely unimpaired and is a very pleasant man, who willingly agrees with anything that is said to him, even if it is in direct contradiction with something he has previously agreed with just moments before. A dispute about his support needs developed between family members, one had been heavily involved and was knowledgeable about him, and the other party who had not been very involved and admitted that they did not understand or accept the impact of his severe brain injury.

Our organisation referred this young man to an independent expert (neuropsychologist) in acquired brain injury who ascertained that he lacked capacity with regards decisions taken about his support needs. As such we held a best interests meeting and invited the local authority to join the meeting. We wished to ensure that they were fully informed regarding matters relating to this vulnerable man. What unfolded subsequently took over two years to resolve, cost significant amounts of money and time and led to family disputes being heightened. Amongst the issues to occur were:

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
A social worker visited without informing any party, met the client and thought he had capacity. She was subsequently provided with reams of paperwork relating to the client’s condition. She rejected the combined decades of experience of acquired brain injury (from the doctors, neuropsychologist, occupational therapist, case management and support team) for her own assessment that did not mention cognitive or executive problems or acknowledge his loss of insight.

An IMCA was appointed who visited, said the client “looked alright to him” and when he was provided with detailed documentation, stated that he did not like labels and liked to “see the person”. Client centred work is key to what we do too. It is important to understand the client to be able to see them and see what they require to maximise their potential and functional independence.

Neither the social worker nor IMCA had any recognition that their presence and the questions they asked the client created the responses that they were looking for. The client cannot generate ideas but simply agrees with what is said to him.

This was eventually resolved via the Courts who deemed that all decisions would be taken away from the local authority. This took time and money to establish, created distress for the client and led to an entrenchment of family disputes.

The client in this example had previously been provided with over 6 years input and had been supported to gain significantly more functional independence throughout this period, reducing his dependence on staff, increasing his range of community activities and becoming an involved and safe father. At no point during this process did he have full insight in to his needs nor was he able to define what services would support him to make further progress or sustain gains made. Had the social worker’s capacity assessment stood, there would have been a very serious risk that this young man would have been left without the services he required to live successfully in the community and to parent safely.

Specific points raised by the House of Lords:

2. Which areas of the Act, if any, require amendment; and how?

That the notion of a “single decision” be recognised as a false premise. For people with complex needs, behavioural patterns unfold over time. Our clients often do not “decide” to find themselves in certain situations, it is often an absence of decision-making or a consequence of the fact that they may be environmentally governed etc. that leads to complications. There is often no one distinct and discrete decision.

That assessment of brain injured people needs to be undertaken by those with the skills, experience and training. Presently, social workers in statutory services appear to be trained to undertake capacity assessments but not trained to consider the purpose of the assessment or be aware of the underlying condition that they require knowledge of to be able to make the assessment. They also do not appear to follow best practice guidelines to liaise with relevant others to complete the assessment.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
4. To what extent have the five principles of the MCA been implemented in frontline practice? What evidence is available to assess this? Is there a satisfactory balance between enablement and protection?

I would argue that a lack of knowledge of acquired brain injury, of the complex interplay between cognitive and executive difficulties in the context of poor insight, renders it impossible for many statutory workers to adequately assess the capacity of people with an acquired brain injury. Therefore the principles, all of which are very well meaning, are impossible to apply.

With our specific client group the “satisfactory balance between enablement and protection” referred to, is more complicated. What actually appears to happen is that capacity is found by workers without the requisite skills, knowledge and experience and this is used as a way of not providing services. This does not “enable”, quite the reverse, this disables by leaving people with severe and complex difficulties adrift as they have stated that they are fine and do not need input. What is actually assessed is what they say, not what they do or need.

6. Is the Act widely known and understood by professionals required to implement it? How does this differ across different sectors, such as health, social care, banking and others?

As for my answer to point 4, a lack of knowledge of the impact of acquired brain injury means that professionals may be very aware of the Act in and of itself but have no ability to usefully utilise this owing to a lack of knowledge of the condition of the individual who they are assessing.

8. Has the Act ushered in the expected, or any, change in the culture of care?

The greatest change we have observed is the use of the Act, or notions of Capacity, is to provide a context and a framework by which a decision to not support or provide the necessary input to an individual can be justified. I am certain that this was not the intention of the Act but for our client group at least, it is the impact of it.

9. Is there any evidence that the provisions of the MCA affect some groups disproportionately? If so, what data exists to compare representation across different socio-economic groups, Black and Minority Ethnic groups, and gender?

I strongly suspect that the confounding factor of relatively intact (or even high) IQ in the presence of poor insight, or those with fluctuating insight, executive dysfunction and mood swings, means that people with an acquired brain injury are disproportionately likely to have their needs missed in comparison to people with learning disabilities or dementia.

As the assessment process in practice is carried out by people lacking the relevant knowledge, it is ill-informed of the needs and presentation of those with an acquired brain injury. In addition, the assessment process itself is more likely to demonstrate and support “capacity” in that moment, during the conversation, but this is in the abstract and not matched by subsequent action. No consideration is given of previous patterns of behaviour supporting issues over time. The very process of carrying out an assessment in this way is indicative of a lack of knowledge of the impact of acquired brain injury.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
10. Are those directly affected by the Act being enabled and supported to make decisions for themselves to a greater or lesser extent than they would have been in the past?

I believe that people with an acquired brain injury are less enabled and supported as a consequence of the Act. Poorly informed decisions are taken concerning capacity and subsequently brain injured people are left without the input or support they require on the grounds that they “have capacity” to disengage from services and deteriorate. Evidence of rates of acquired brain injury within UK prison populations, homelessness, drug services etc. abound.

15. Are IMCAs adequately resourced and skilled to assist in supported or substituted decision making for people lacking capacity?

Our limited experience would lead us to state that IMCA’s, like social workers, lack the basic knowledge required to support brain injured people.

Conclusion

I hope that the above is helpful to the House of Lords in their consideration and review of the Mental Capacity Act. Please do not hesitate to contact me if further clarification or information is required.

27 August 2013
Head First – Supplementary written evidence

We are writing further to the oral evidence provided to the committee on the 8th October 2013, in particular question 140.

May we firstly say that we were particularly pleased by the fact that acquired brain injury was specifically referenced in this question. Despite the relatively high numbers of people acquiring brain injuries in the UK, and the very serious implications for these individuals, their families and wider society as a whole, the condition remains "invisible", virtually unspoken of and barely recognised. It is our shared contention that the assessment of capacity of brain injured people is a matter of significant concern, particularly when this is undertaken by social workers who lack a basic knowledge of the condition, as the vast majority would appear to.

The response provided to question 140 is constructive in many ways and we are grateful for Ms Ribas-Gonzalez’ comments. There are two main points that stand out for us and these are:

1. Ms Ribas-Gonzalez notes that social workers do not have to carry out capacity assessments in isolation. It is our shared view that in fact it is very important that such assessments are informed by a range of professionals as well as by family and the brain injured party themselves.

   In practice however, we regret to say, this collegiate approach, seeking information and knowledge from those with a specialist interest in acquired brain injury often does not occur; in fact quite the reverse. Specialist knowledge and experience (often developed over decades of dedicated work with this client group) that provides a challenge to the social worker’s "common-sense" view is regularly rejected and frequently actively fought against.

   It is our shared experience that a lack of basic knowledge of the impact of cognitive and executive impairments, in particular if the brain injured party demonstrates intellectual awareness but not insight, means that assessments are carried out in a way that is contra-indicated by the condition itself.

   Whilst we would therefore fully endorse Ms Ribas-Gonzalez’ contention that capacity assessments for people with an acquired brain injury can and perhaps should be a more collegiate endeavour, co-produced by relevant people with the experience and knowledge required, this is not the case at present. Social workers’ lack of knowledge is so profound that there very regularly is no understanding of entire concepts such as poor insight and executive impairment. When combined with a lack of knowledge that other people, specialists, may hold such information and may be able to assist, this sets in train conflict that is both costly and potentially very dangerous.

2. Ms Ribas-Gonzalez helpfully identifies that there is a need for "more specific and hands-on training into carrying out assessments and real-life situations." (Possibly "in real life situations" was meant?)

   We would agree, at least in part, with this statement.

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It is our shared experience that social workers are provided with training on how to complete a capacity assessment form.

Accurate assessment of needs and functioning post acquired brain injury is a complex process as the injured party (and sometimes the family too) does not always have insight into the nature of their difficulties but may well have intact IQ and possess an intellectual awareness of their condition. Therefore the injured party may look and sound as though they understand the situation and, in the constructed setting of an assessment, is supported to sound competent and make decisions that are reasonable.

We do not doubt that in a structured and guided conversation lead by a well-intentioned and intelligent other, such as a social worker, some of our brain injured clients can demonstrate that they understand information and decisions, can retain information for the period of the dialogue and can even be supported to weigh up the pros and cons of decisions.

The difficulty arises in the absence of the externally managed and structured discussion when such clients need to use the information to make potentially complex and inter-related decisions that take place over time and have an emotional content/driver and that are not discrete, clinical and abstract ones in unreal settings.

There is a very real risk therefore that the capacity of brain-injured people is measured in the abstract and extrinsically governed environment of an assessment and it is the stated intention that is assessed, one that is in fact supported to made, rather than actual functioning. The process of assessment itself provides the compensatory strategy required to facilitate the generation of evidence of capacity and "good" decision-making. It is our shared experience that when this is highlighted to social workers, the absence of underlying background knowledge prevents this from either being understood or incorporated within the assessment or decision-making process. Sadly in fact highlighting this has caused conflict with the social worker viewing this as a challenge to be fought rather than support to undertake an accurate assessment as it is intended.

An alternative risk is the fact that rather than the brain injured persons capacity being assessed, it is the capacity of those who support him/her that is found to be present. Often, for example, our clients do not deal with their correspondence, others do, most often family. An absence of difficulty with management of such matters is seen as evidence of capacity when in fact this is not the case. Whilst deferring this to family may be viewed as a sensible decision this can in fact be a "default" decision, not a decision at all but based upon an absence of a decision. Family take over because they have to, there is not an alternative.

It is our experience that social work assessments of capacity are very simplistic, often making no reference to cognitive or executive impairment and taking no account of the possibility of difficulties with issues such as reduced insight/variability of performance.
Whilst therefore agreeing with Ms Ribas-Gonzalez with regards to the value of specialist training we would state that this training needs to be focussed on the impact of acquired brain injury, on methods of assessing people with an acquired brain injury and by providing information relating to who may support and help social workers with this task, not simply how to fill in a capacity assessment form as would appear to be the case now.

We have attached a selection of comments made by colleagues from across the country following receipt of the evidence provided to the committee on the 15th October 2013.

We hope that this letter is helpful for you and your colleagues when undertaking the review of the Mental Capacity Act and ask that you do not hesitate to contact us should you require any further information or clarity.

Mark Holloway DipSW MA  
Brain Injury Case Manager and Care Expert  
Head First (Assessment, Rehabilitation & Case Management) LLP

Jackie Dean Dip COT  
Neuro-Occupational Therapist, Brain Injury Case Manager and Care Consultant  
Director N-Able Services

Professor Michael P Barnes MD FRCP  
Professor of Neurological Rehabilitation  
Hunters Moor Neurorehabilitation Centre, Birmingham  
Clinical Director, Christchurch Group

Jo Clark Wilson DipCOT MAE  
Rehabilitation Specialist, Brain Injury Case Manager and Care Expert  
Director Head First (Assessment, Rehabilitation & Case Management) LLP

Dr. Martyn Rose FRCS  
Consultant in Neuropsychiatric Medicine

Professor Michael Oddy MSc PhD FBPsS  
Director of Clinical Services, Brain Injury Rehabilitation Trust

Dr. Michael Dilley MB BS BSc MSc MRCPsyCh  
Consultant Neuropsychiatrist & Lead Clinician, National Neuropsychiatry Service, Maudsley Hospital, South London & Maudsley NHS Foundation Trust & Blackheath Brain Injury Rehabilitation Centre, The Huntercombe Group

Dr. Howard F Jackson B.Sc., M.Ciin.Psychol., Ph.D., AFBPS, C.Psychol.  
Consultant Clinical Neuropsychologist  
Founder and Clinical Director, TRU.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
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It is the community settings where we have more of the issues, as there are often no other specialist services around or, if so, they are not incorporated in the process, as the client might not be involved with statutory services. In care facilities and acute settings, the problems clients have may be more recognised by those at the care home. In the community, the complexity will not be appreciated.

Are you aware that XX Mental Health Trust have just stated that Mr. X has capacity (even though three ABI specialists have stated he does not) as they do not know what to do with him? It is stated his actions are a life choice, so they do not need to be involved. It is likely to be judicially reviewed. (Brain Injury Case Manager A, over
I'm reminded of our shared client Mr. Y - the social worker had no knowledge of cognitive and executive difficulties and impaired insight of the client AND no knowledge of the funding arrangements, the role of Deputies and Court of Protection or of his support/rehab package. This led her to allege financial fraud I abuse I safeguarding issues and so did not consult with the family or to undertake joint assessments with health professionals about the client’s impairments. (Consultant Clinical Neuropsychologist B, over 30 years ABI experience)

Not to mention the cost implications of addressing such erroneous judgments – both in terms of time and taking it to the Court. (Brain Injury Case Manager C, over 30 years ABI experience)

AND of course all those initial problems with them blocking Mr. Z getting into appropriate substance misuse and ABI rehabilitation at TRU on the erroneous judgment that he had capacity. But look at him now. I have several cases now where we and other experts and relations believe the person to lack capacity but the social workers think otherwise. Hence a stalemate and the need to go Court of Protection. We need at least legislation that ensures that those with specialist knowledge and experience in ABI should take precedence over generic social and health staff in the decision making process. (Consultant Clinical Neuropsychologist D, over 30 years ABI experience)

I think that most statutory social workers do not have, or see the need to use available brain injury specialists in their area, if they are available, to call on to undertake these assessments. If social workers saw the implications of their actions, it is potential abuse! We have the evidence that some social workers state clients have capacity, as they do not know how to deal with them or want to pay for appropriate support - and on more than one occasion have stated it is their life choice! (Brain Injury Case Manager E, over 30 years ABI experience)

I have one positive experience of joint working with a social worker in a very complex capacity and safeguarding issue. The social worker and her manager were fantastic, they recognised what they did not know and joint worked with us for the benefit of the client. This is the only positive experience I have, the rest have been terrible, leading to conflict, use of the Courts and serious expense. (Brain Injury Case Manager F, over 20 years ABI experience)
Headway, Alzheimer’s Society and Mind – Oral evidence (QQ 90 – 105)

Transcript to be found under Alzheimer’s Society.

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On the 16th July 2013, Headway's Chief Executive, Peter McCabe, gave evidence at a House of Lords Select Committee inquiry on the Mental Capacity Act and how it is being implemented.

Peter presented the views and opinions of Headway service users and key stakeholders with direct experience of the Mental Capacity Act (MCA/The Act) while also highlighting areas where the Act needs improving in order to acknowledge the specific challenges faced by people with brain injury.

The Select Committee's aim is to review the MCA, which was introduced in 2005, and work towards implementing any important changes that may be necessary.

This document summarises the evidence Headway presented to the Committee.

This section addresses some of the questions that were discussed at the Committee meeting. Further discussion is included in the Key issues section below.

I. The Act

At the time it was passed the Mental Capacity Act was widely viewed as progressive and welcome legislation. Has the Act lived up to these expectations? Are there benefits or problems that were not foreseen at the time the legislation was passed?

The Act was, and continues to be, generally well-received and it is recognised that it performs a vital role in safeguarding the interests of many people who lack capacity.

There is little specificity to brain injury however, and gaps in service provision and general understanding of this complex condition undermine the principles of the MCA.

Advocacy

Independent Mental Capacity Advocate (IMCA) services were initially hailed as a means of supporting people, and Headway welcomed their introduction. However, in reality these services are extremely limited and officers are very often not specialists in brain injury.

Making decisions on behalf of someone who lacks capacity

The process of applying to make decisions on behalf of someone who lacks capacity is long, expensive and complicated. While we recognise that it is vitally important that these decisions are made with every possible care, we do have concerns that the complexity of the system may deter people from seeking appropriate authorisation, particularly in less clear-cut financial and welfare situations.

Treatment decisions

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The process of making important life-prolonging and/or advance medical treatment decisions is extremely complex. We have heard a number of reports from families that are fighting to get appropriate treatment for relatives, with significant further distress being caused while relatives of those with very severe brain injury are in reduced states of consciousness.

What changes, if any, would you make to the Mental Capacity Act 2005 or Code of Practice?

In our consultation with Headway service users and stakeholders with experience of the MCA, we have identified a number of changes that could make the Act more appropriate for people with a brain injury.

These include:

- Simplify guidance on best interest decisions
- Create brain injury specific IMCAs and make advocacy services available to all
- Ensure mental capacity assessments are performed by appropriately trained staff, particularly for those people with complex conditions such as brain injury
- Simplify the process of appointing deputies and ensure more regular supervision
- Provide additional training and clarification on the Act for medical professionals so they fully understand their responsibilities

II. Understanding and use of the Act

Previous witnesses have commented on differences in understanding of the Mental Capacity Act among professional groups. Does this reflect the experiences of those that you work with? Does this change for different settings, such as hospitals, types of decision or for different types of impairment or for those with fluctuating capacity?

The lack, or inconsistency, of understanding of the MCA is a major problem for implementation of the Act. Professionals at all stages of care may be required to either perform or refer patients for capacity assessments, be it for normal everyday decisions, or more complex treatment and care issues.

We feel it is essential that anyone who may reasonably have involvement in capacity issues should receive adequate training, both in the MCA and the medical condition of the person they represent.

Too many people with brain injury are being referred for inappropriate care or no treatment at all. We regularly hear reports of individuals being placed in residential units specialising in mental health issues, rather than brain injury, putting them at risk of inappropriate treatment and care decisions made on their behalf.

To summarise:

- There is a lack of consistency with capacity assessments
- There is a disparity of understanding among medical professionals

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Are families, carers and individuals who may lack capacity aware of and able to access their rights under the Act, including through the role of Independent Mental Capacity Advocates and the Court of Protection?

As discussed, we do not feel that this is always the case.

Our helpline regularly receives enquiries relating to capacity issues - often from relatives of people with severe brain injury who have received no information or support to help them make decisions on behalf of a loved one.

This lack of information in the early stages can lead to big problems - these could range from treatment decisions being made that do not take into account the patient's wishes and values, to financial hardship incurred because no appropriate measures were put in place following the loss of a household wage-earner.

Headway has produced literature to try to provide this information to people. However, IMCA services remain elusive for many, and the process of applying to the Court of Protection is unduly complicated.

It is clear that the provision of IMCAs with specialist knowledge of brain injury would be of great benefit to people with a brain injury, their families and carers.

Has the role of the Independent Mental Capacity Advocates succeeded in providing a voice for those who have no-one to speak on their behalf, and an additional safeguard against abuse and exploitation? Do you have any concerns about the varying rates of referral across different local authorities?

As previously discussed, the concept of the IMCA service is a very good one. When navigating such a complex area, families, who are often going through an extremely difficult time, need good quality specialist support.

However, availability of these services is limited, which makes it very difficult for us to get accurate feedback from our service users.

Many IMCA services are run by mental health and learning disability organisations rather than brain injury specialists. We would suggest that measures be put in place to increase access to IMCA services, including commissioning of those with knowledge of brain injury.

Some service users have raised the issue of a need for independent advisors to be available in acute care settings to assist families in dealing with the complexities of the MCA at times of huge distress and anxiety. We feel the Act would be improved if it recommended or required the provision of IMCA-like services in all acute care units, and/or Citizens Advice Bureaux.

III. Assessments of Capacity and Best interests

We have heard contrasting views on how easy it is to assess capacity in practice and it has been suggested that some practitioners conflate the assessment of capacity with an assessment of best interests.

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What is the experience of your client group of how capacity and best interests are assessed in practice? Are there issues particular to specific types of impairment, such as acquired brain injuries or dementia, particular settings or particular professionals that affect capacity assessment?

Brain injury is an extremely complex condition. Individual needs vary greatly, with the wide-ranging effects of the condition, psycho-social factors, and the availability of a support network leading to big differences in capacity.

People often present well to assessors in informal assessments lasting up to half an hour, but the reality is that short meetings often do not accurately reflect the individual's day-to-day life.

Could environment skew assessments? Is it possible a person with a brain injury could perform disproportionately well in an assessment carried out in his/her own home compared to conducting the interview in a unusual setting outside of their comfort zone, such as a new rehabilitation unit? Are brain injury-related issues such as anxiety and fatigue taken into account in such situations? Are people who lack insight into the effects of their conditions adequately supported in the MCA and related capacity assessments?

Are the law and Code of Practice sufficiently clear for practitioners and informal carers to follow? Are assessments of capacity and/or best interests happening in accordance with the Act?

There is a disparity of understanding, which is discussed throughout this document.

The need for families, civil partners and carers to be consulted and involved in decisions about best interests was stressed by a number of submissions to the pre-legislative scrutiny committee.

Key issues

This section provides further detail on our feedback regarding four key issues of the MCA:

- Autonomy vs protection
- Assessment of capacity
- Gaps in understanding
- Advocacy

This is intended as more detailed evidence to support the questions presented above. As such, much of the information will overlap.

**Autonomy vs Protection**

This is already a key aspect of the Act and it is proving very difficult to strike the correct balance on such a delicate principle. It's a principle that is at the heart of the MCA.

At what stage does a person need protecting from their own decisions? If they are deemed to have capacity, shouldn't they be able to make their own choices, regardless if seem by some to be the 'wrong' choices?

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An example we received from one solicitor is that a person may have capacity to make a decision to purchase a large, expensive household item, such as a TV. However, they may lack capacity to understand the consequences of making a number of similar decisions, which may lead to financial difficulties in future. One single decision to make a one-off purchase may be fine, but does the individual have a sufficient understanding of budgeting to know that the purchase will impact on the individual’s ability to make further large purchases?

The MCA must make better provision for 'linked decisions’ such as these.

It should also make specific provision for some of the often hidden effects of brain injury, such as lack of awareness and insight, impulsivity, inflexibility and obsessional behaviour. These serious effects can be extremely difficult to assess, particularly for professionals without the correct level of specialist knowledge, but yet can have a major impact on welfare.

**Assessment of capacity**

People with brain injury often ‘present well to assessors in informal assessments lasting up to half an hour’, but the reality is that short meetings often do not accurately reflect the individual’s day-to-day life.

Could environment skew assessments? Is it possible a person with a brain injury could perform disproportionately well in an assessment carried out in his/her own home compared to conducting the interview in a unusual setting outside of their comfort zone, such as an office? Are brain injury-related issues such as anxiety and fatigue taken into account in such situations?

**Gaps in understanding**

Currently, it is often left to healthcare professionals to make decisions in the best interest of a patient lacking capacity. However there are significant gaps in knowledge among healthcare professionals when it comes to brain injury.

Too many people with brain injury are being referred for inappropriate care or no treatment at all. We know of individuals placed in residential units specialising in mental health issues, rather than brain injury. This is one reason that Headway has launched our Approved Provider scheme, to assess units against detailed criteria that ensure their expertise in brain injury.

Similarly, Headway has recently worked in partnership with the RCGP to try to assist GPs in diagnosing and referring patients affected by brain injury, again borne of the need to improve healthcare professionals’ understanding of this complex condition.

Best practice choices must be based on having all and appropriate information. The Act must take into account the fact that this is not currently the case.

**Advocacy**

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
This issue has been discussed in detail above, but ensuring that family members and carers of people who lack capacity are adequately supported is key to the successful implementation of the MCA.

Headway is calling for the MCA to be strengthened to require a minimum provision of IMCA services, with specialist training in the condition they are supporting, and available at all relevant points including critical care units.

Feedback from professionals

In compiling our evidence, we sought the views of a number of professional stakeholders, including legal professionals who are involved in capacity and best interest decisions for their clients.

The following points summarise the feedback we have received from a number of professionals on how the MCA is working, the challenges they and their clients face, and how things could be improved. These points have been selected as they echo the feedback we have received at Headway over a number of years.

There is a general feeling that the MCA has been a success, and provides valuable support and protection to people who lack capacity. The MCA has put principles of best practice into law and helped clients to be involved in the decision making process as much as possible, while ensuring decisions made on their behalf are in their 'best interests'.

The MCA allows common sense to be applied, which ensures it does not act as a barrier to people receiving the support they need. This is important legislation which successfully helps to preserve the basic rights and independence of people with brain injury, and offers vital support to their family and carers.

The MCA requires that 'all practicable steps' are taken to help a person make a decision for themselves. There is a feeling that this is at odds with other aspects of the Act, which require decision makers to encourage a person to participate only 'so far as reasonably practical'. There could be more clarification on the level of involvement a person is required to have, in particular with relatively minor decisions.

It can be difficult for professionals and family members to judge whether a person is making an 'unwise' decision, which the MCA protects their right to make, or whether they lack the capacity to make a decision. More support and clarification on these definitions would be helpful, although this area will always be difficult to get right.

Similarly, there is some concern that the presumption of capacity can, in some cases, lead to people with a brain injury being vulnerable. This is particularly the case where large settlements are awarded and in reality they find it extremely difficult to handle large amounts of money.

The MCA is very good at dealing with individual decisions, but there is a feeling that it could be strengthened to take into account a person's ability to understand the consequences of a series of decisions over time.

For instance, a person may have capacity to make a decision to purchase a large, expensive
household item. However, they may lack capacity to understand the consequences of making a number of similar decisions, which may lead to financial difficulties in future, i.e. one single decision to make a one-off purchase may be fine, but that purchase will impact on the individual's ability to make further large purchases. This concept may not be fully understood by the individual.

We suggest a new section 3(4)(c) which incorporates "the possible consequences of the decision alongside another decision or decisions made in the past or future".

Section 16(4)(a) of the MCA specifies that "a decision by the Court [of Protection] is to be preferred to the appointment of a deputy to make a decision". We feel deputies offer the opportunity to make decisions much more quickly with the person's best interests in mind. In reality, deputies are appointed in most property and financial affairs cases, and the Act should be amended to reflect this.

We have concerns about reports of a reduction in Court of Protection resources that has led to a significant reduction in the supervision provided to deputies. It is vital that spot checks and inspections are made on a deputy's activities in order to protect the welfare of people who lack capacity. Similarly, regular checks provide important support to assist deputies in their role.

We would ask that the MCA includes a requirement that inspections are made at appropriate intervals to ensure the protection of vulnerable clients – and indeed the deputies themselves.

Feedback from service users

In producing this report we gathered feedback from our members, asking them to tell us their views on the MCA.

Mrs A:

Mrs A's sister is in a minimally conscious state following a catastrophic brain injury. Her experience of the Mental Capacity Act relates to the general and life-sustaining treatment and care decisions being made about her sister by the clinical team, following her admission to hospital and later a care home.

Mrs A feels that in practice the MCA is not working due to a lack of staff training, a clash with established practice and organisational structures which make the incapacitated particularly vulnerable. She highlights the following issues:

1. There is a need for more training for staff in health and care settings - good, high-quality training with personal stories that show it matters, not online modules that people simply tick off. This is because it's not just a question of information but a need for cultural change.

2. There is a need for good information for families so they understand their role and the patients' rights.

3. Organisational changes are needed if the MCA is to work – e.g. (a) better transfer of
information between clinicians and sites (as person themselves cannot be their own 'continuity of care' person, (b) advocates in hospitals for every incapacitated patient.

4. Possible changes to the MCA (e.g. to clarify that a 'best interests' decision does not always mean intervention to sustain life, or vice versa – must take account of patient’s own pre-injury views and values.

5. Advanced Decisions (ADs) and promoting end-of-life planning: Although the MCA made provision for ADs, the terms are so stringent (and public information so limited) that this isn’t working well. There is a need to re-visit the terms of what makes a valid and applicable AD, provide public information and support ADs in writing. Also clinicians should not treat the absence of an Advance Decision as meaning the person’s expressed beliefs (as reliably documented in other ways) have no influence in relation to life-sustaining treatments.

6. More generally, the danger of under-treatment is well documented (because medics make 'quality of life' judgments against profoundly disabled people). The other side of the coin is the danger of over-treatment - based on an equal disregard for the person’s own values and beliefs, and a fear of being sued. Medics made comments to me like 'no one has ever been sued for saving a life'. We need clinicians to be supported in ways that lead to neither over-treatment nor under-treatment.

My general personal impression is that staff I encountered were ignorant of their duties under the MCA - and could not believe/did not want to believe what those duties were when I tried to inform them.

Staff defined a 'best interests' decision as a 'clinical decision' - and just saw it as a matter of clinical judgment. From the moment of my sister’s accident it was as if she belonged to them, they were not interested in what we knew about her and her wishes. I can understand this in the immediate emergency but this went on for months and months, it was a constant battle.

I think this was a combination of ignorance about the MCA, and lack of time, and business as usual. Also it was unclear who the decision maker actually was for most things, so in the absence of her ability to represent herself at the time, my sister was just an object to be processed.

The system is not well adapted for patients without capacity - they need an advocate on the spot who can collect relevant info from the family and who knows the system. Because they didn’t collect and process what she would have wanted, and anyway had a fear of allowing her to die, they acted with disregard to her prior expressed wishes.

Comments from other service users

Other service users provided us with brief accounts of their experiences and perceptions of the MCA:

Mrs B:

"Luckily my hubby has just passed his mental capacity test. If not then the court of protection would have taken over. The procedure of the test lasted approximately one
hour, it was actually done very well. It wasn’t invasive and it’s more common sense questions. Everything was discussed properly to make my hubby understand it properly.”

Mrs C:

"I think that Act might have saved my bacon. I was saved by a clause the judge handed to me because he could see how bad things had become. If it wasn’t for the olive branch that the judge handed me I would have my tribunal rejected."

5 September 2013
Health and Care Professions Council (HCPC) – Written evidence

1. Introduction

1.1 We welcome the opportunity to respond to the Committee’s Call for Evidence.

1.2 The Health and Care Professions Council is a statutory UK-wide regulator of health, social work, and psychological professions governed by the Health and Social Work Professions Order 2001. We maintain a register of professionals, set standards for entry to our register, approve education and training programmes for registration and deal with concerns where a professional may not be fit to practise. Our main role is to protect the health and wellbeing of those who use or need to use our registrants’ services.

1.3 We regulate the members of 16 professions.
   - Arts therapists
   - Biomedical scientists
   - Chiropodists / podiatrists
   - Clinical scientists
   - Dietitians
   - Hearing aid dispensers
   - Occupational therapists
   - Operating department practitioners
   - Orthoptists
   - Paramedics
   - Physiotherapists
   - Practitioner psychologists
   - Prosthetists / orthotists
   - Radiographers
   - Social workers in England
   - Speech and language therapists

2. Our comments

2.1 We have confined our comments to responding to the following question which is most relevant to our role as a professional regulator.

Q. Should other regulatory bodies, such as health and social care professional regulators, be acting in this area?

2.2 We do not consider there is a need for the professional regulators to undertake any additional roles in relation to the Act, over and above their existing statutory roles in investigating and adjudicating on matters where a registered professional’s fitness to practise has been brought into question.

2.3 We are able to consider concerns about a registrant to the effect that their fitness to practise is impaired in some way. This means that we are able to consider any concerns which might arise from time-to-time about a registrant’s conduct or

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competence in relation to discharging their duties under the Act. We consider each fitness to practise case referred to us on an individual basis in order to decide whether we need to take any action to protect members of the public.

2.4 We have a memorandum of understanding with the Care Quality Commission (CQC) to help facilitate information exchange between both organisations on matters which might be relevant to each organisation’s regulatory responsibilities.

2.5 Should you have any questions about our submission, please contact us.

2 September 2013
In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
1. **Introduction**

1.1 The Health Research Authority (HRA) was established in December 2011 in England to promote and protect the interests of patients and the public in health research. We strive, with partners, to make sure the UK is a great place for health research. Recognising that many members of the public want the opportunity to participate in research, we aim to ensure that health research involving them is ethically reviewed and approved, that they are provided with the information that they need to help them decide whether they wish to take part, and that their opportunity to do so is maximised by simplifying the processes by which high quality research is assessed. In doing this, we will help to build both public confidence and participation in health research, and so improve the nation’s health.

1.2 To provide some context for our response during the period 1st April 2012 to 31st March 2013 HRA Research Ethics Committees (RECs) reviewed 322 applications involving adults lacking capacity. These involved research in the following areas:

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<tr>
<th>Research Category</th>
<th>No. of Applications</th>
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<tr>
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<tr>
<td>Clinical Trials of an Investigational Medicinal Product (CTIMP)</td>
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<td>Research Database</td>
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<tr>
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1.3 In preparing this response the HRA has sought comments and advice from the Chairs of Research Ethics Committees flagged for the review of research falling under the Mental Capacity Act or Adults with Incapacity (Scotland) Act and the National Research Ethics Advisors’ Panel (NREAP). The panel is comprised of 7 members including individuals with expertise in moral philosophy, research ethics committees, patient and public involvement and clinical research. The panel is independent but hosted within the HRA and is a resource available to all RECs, funded by the UK Health Departments, within England and the devolved nations. The panel’s primary role is to help research ethics committees deliver robust, consistent and fair decisions through consultation with all stakeholders, including RECs.

1.4 Please note that in responding to this call for evidence the HRA has confined its comments to those areas of the Mental Capacity Act 2005 that are directly related to its work i.e. the provisions that relate to the conduct of health research and its review by appropriately constituted Research Ethics Committees.

2. **HRA RESPONSE:**

\[102\] N.B. Both clinical trials of an investigational medicinal product and gene therapy trials which involve adults lacking capacity are regulated by the Medicines for Human Use (Clinical Trials) Regulations (2004) rather than the Mental Capacity Act 2005.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Overview and context

Q. 2. Which areas of the Act, if any, require amendment; and how?

2.1 **Principle (5):** “An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests”.

Since participation in research can rarely be said to be directly in the participant’s best interests it would be useful to have some additional clarification, perhaps in the Code of Practice, as to how this principle ought to be understood in the research context. For example, it might be suggested that participation in research ought not to be against the participant’s interests. In addition, a decision to enter P into a research project ought to be compatible with their wider interests i.e. it is the kind of decision they would have made if they had capacity.

2.2 **Section 31(2):** Further clarification, in the MCA Code of Practice (April 2007), for the following criteria listed under S31(2):

“(2) The research must be connected with—
(a) an impairing condition affecting P, or
(b) its treatment.”

It would be useful to have some discussion and examples of the kinds of connections the research must have with an impairing condition or its treatment. For example:

- Where it seems reasonable to enter people with a range of impairing conditions into a study that is looking at treatment for a common complication of impairment but where that treatment is not directly related to the impairing condition.
- Where it is necessary to do research of basic science and thus is not directly related to an impairing condition or its treatment but could not be done on people who have capacity.
- Where research is for a treatment that is for a condition with no necessary connection to an impairing condition but many people in need of that treatment will also have an impairing condition e.g. traumas such as compound fractures following road traffic accidents (RTAs) or fractured femurs where dementia is a factor (but where the other section 31 clauses are met).

2.3 **Section 31(5):** Examples should be given in the MCA Code of Practice as to how to understand such terms as ‘negligible’, ‘disproportionate’ and ‘unduly invasive or restrictive’ as used in the following paragraphs within the Act:

“The research must—
(a) have the potential to benefit P without imposing on P a burden that is disproportionate to the potential benefit to P, or
(b) be intended to provide knowledge of the causes or treatment of, or of the care of persons affected by, the same or a similar condition.

(6) If the research falls within paragraph (b) of subsection (5) but not within paragraph (a), there must be reasonable grounds for believing—
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(a) that the risk to P from taking part in the project is likely to be negligible, and
(b) that anything done to, or in relation to, P will not—
   (i) interfere with P’s freedom of action or privacy in a significant way, or
   (ii) be unduly invasive or restrictive.”

2.4 S32 (3): Nominated Consultee (NC).

Changes are required to the clarification of the role of the Nominated Consultee as given in: “Guidance on nominating a consultee for research involving adults who lack capacity to consent” Issued by the Secretary of State and the Welsh Ministers in accordance with section 32(3) of the Mental Capacity Act 2005 (February 2008).

This guidance is useful but there could be more flexibility and, perhaps, distinct clarification given in this document for the Nominated Consultee (NC). For example a NC is often used when it is not possible to find a Personal Consultee yet the guidance tells the NC to effectively make use of personal contacts of the patient to satisfy themselves of the patient’s values and prior wishes etc. This makes the role challenging and often impossible when personal contacts of the patient cannot be found/contacted. Since the NC is unlikely to know the patient it would be useful if the (suitably qualified) NC could comment on other aspects of the ethics/risk assessment of entering ‘P’ into a research study.

2.5 Section 32 (8) & (9): Emergency provisions.

The possibility of entering a patient into a research study under emergency provisions is a very important facility. However the emphasis on the term ‘a matter of urgency’ might give too much emphasis to life-endangering/trauma related studies. A term such as ‘time critical’ might be better understood as allowing research for which time was a factor in enabling the study to happen but was not related to any urgent or immediate needs of the patient. The term ‘time critical’ (with appropriate guidance in the Code of Practice) would allow greater flexibility for a range of studies to be undertaken.

Q. 3. At the core of the MCA are its principles and definitions of capacity and best interests. Are these appropriate?

2.6 Principle (5): “An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests”.

Since participation in research can rarely be said to be directly in the participant’s best interests it would be useful to have some additional clarification, perhaps in the Code of Practice, as to how this principle ought to be understood in the research context. It might be suggested that participation in research ought not to be against the participant’s interests. In addition, a decision to enter P into a research project ought to be compatible with their wider interests i.e. it is the kind of decision they would have made if they had capacity.

Implementation
Q. 6. Is the Act widely known and understood by professionals required to implement it? How does this differ across different sectors, such as health, social care, banking and others?

2.7 Members of Research Ethics Committees undertake specialist training to consolidate and increase their knowledge of the Act.

30 August 2013
In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
1. I am not legally qualified. Having been a scholar in Natural Sciences at Magdalen College, Oxford, I graduated in 1981 with a degree in Physics Specialising in Atomic, Nuclear and Theoretical Physics. I founded my first business in 1983 – John Hemming & Co, JHC – which is a software house which now employs over 250 people with a turnover in excess of £20 Million per annum. I was a City Councillor on Birmingham City Council from 1990-2008 being Deputy Leader of the Council from 2004-5. I was elected as MP for Birmingham, Yardley in 2005 and re-elected in 2010. I founded the Justice for Families Campaign in 2006 because I was concerned about the low standard of decision-making in the family division mainly as a result of flawed evidence heard in secret courts.

2. As someone who is well known to be concerned about some of the decision-making in the family division I am frequently contacted by people who believe their cases to be miscarriages of justice. Often I agree with them, but not always.

3. Although the more general problem within the family division rests on the low academic standard of much of the expert evidence and the conflicts of interest which apply to the authors of much of the expert opinion, this problem becomes more acute where the issues of Mental Capacity are engaged.

4. Whereas I have wider concerns about the operation of the Mental Capacity Act 2005, my initial concern rests around the question of assessments of capacity. The Mental Capacity Act added to the test identified in Masterman-Lister v Brutton & Company. However, it is my view that in practise there are many cases where the operation of this test is scientifically flawed.

5. The first case I considered was that of XXXX XXXX who I assisted in taking her case through the court of appeal, the judicial committee of the house of Lords and to the European Court of Human Rights. From a scientific perspective the fact that there exists a report which indicates that she does have capacity, her GPs conclusion that she had capacity and also my personal assessment of her ability to understand and present her own case – as she did in the court of appeal – raises questions as to the conclusions of the judicial processes to date. She did not have any practical opportunity to challenge the assessment of capacity before the adoption of her daughter. I was actually quite shocked as to what had happened. In essence we have had a judicial process which has been through three levels of appeal which has managed to keep the truth out at each stage.

6. I have continued to meet people who assert that their capacity has been wrongly removed. There is only one case that I am personally aware of where a mother (XXXX XXXXX) was wrongly asserted to have lost capacity by her own barrister (as a result of Querulous Paranoia) and managed with the assistance of a Mackenzie Friend introduced to her by me to contest the removal of capacity.
7. The initial flaw is within the process whereby someone’s capacity is removed. If they are lying in a coma it is not really a difficult issue. However, if a party faces an attempt to remove their capacity then this is a really difficult issue to fight. Solicitors generally refuse to assist people who have had their capacity removed. It is often not possible to obtain financial assistance to instruct an alternative expert. Frequently people who face an attempt to have their capacity removed are not that bright and really don’t know how to handle the situation. The official solicitor has generally ignored requests to reassess the removal of capacity and the system is pretty well an unstoppable juggernaut.

8. It is not normal practise in the family courts for people to be able to obtain a second opinion. In the case X v Croatia, for example, X was able to get a second opinion. However, UK citizens have no right to a second opinion.

9. The government also have been uninterested in obtaining statistics about challenges to capacity. See the following parliamentary question:

**JUSTICE**

**Civil Proceedings: Mental Capacity**

**John Hemming:** To ask the Secretary of State for Justice (1) how many people whose litigation capacity was challenged were found (a) incapacitous and (b) to actually have capacity in each year since 2005; [131247]

(2) how many people have applied to have their litigation capacity reinstated in each year since 2005; and how many of those applications were granted; [131248]

(3) how many times the Official Solicitor has been requested to review his appointment for a person deemed not to have litigation capacity in each year since 2005; and in how many cases he has concluded that he was wrongly appointed in each such year; [131249]

(4) how many people who were found to be incapacitous had a litigation friend appointed in each of the last five years. [131250]

**Mrs Grant:** The information requested is not available centrally and can be obtained only at disproportionate cost.

10. There is little accountability for the Official Solicitor as he is only accountable to the Court which is secret anyway. Furthermore he appears to be the default litigation friend rather than litigation friend of last resort.

11. There are also difficulties more generally with DOLS and IMCAs in that they are subject to conflicts of interest that are ignored. However, the lack of transparency does not help.

12. Additionally parties may be imprisoned for taking their relatives to see solicitors as happened in the case of Wanda Maddocks in respect of her father John Maddocks.

13. I would be happy to provide more evidence for the committee. However, I believe that the above and my background papers give a good starting position. Generally there is a lot of complacency about how the system operates which is only possible because the system has little transparency or accountability.

3 July 2013

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Dr Pauline Heslop, Team Manager of the Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD), Bristol University, and Dr Margaret Flynn, Independent Consultant, former Chair of the serious case review into Winterbourne View

Q56 The Chairman: I would like to welcome you. We are a few minutes late as we started much later with the other witnesses, although we have caught up slightly. I apologise if you have been kept waiting. We should remind you, as I am sure you are aware, that the proceedings are being recorded and broadcast, as well as being recorded by shorthand. At the end of the evidence a transcript of your evidence will be made available to you, so if there are any minor alterations and corrections that you wish to make, you will be given that opportunity.

Before you start, I will explain, as I am sure you are aware, that the Committee was set up to consider the report on the Mental Capacity Act. Members were very anxious to hear from you as authors of very major and significant reports which have wide implications for the care system in general. I do not wish to underestimate the significance of these reports, but in this Committee and in this session we seek to see what lessons can be learned from your reports for the implementation of the Mental Capacity Act. I know that the reports are

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much wider and much more significant than that, but that is the sort of primary interest at the moment in this Committee. Going on from that, can I ask both of you what are the key findings and recommendations of your inquiries which are relevant to the Mental Capacity Act?

**Dr Pauline Heslop**: Thank you. Overall, from the inquiry conducted into premature deaths of people with learning disabilities we found poor understanding of and adherence to the Mental Capacity Act both in professionals and in family members. However, there were some examples of good practice, and I will be happy to share those with you later. Where the Act was working well, it appeared to be down to the knowledge and understanding of individuals or specialists such as specific disability liaison nurses rather than spread more generally throughout an organisation. There were four main concerns that we took from the confidential inquiry. The first concern was regarding the lack of assessments of capacity for individuals or documentation of that assessment. It may well have been that assessments took place, but they were not documented. In some cases we found that decisions that a person lacked capacity had been made on the basis of a person's appearance or behaviour, or because they had been assessed as lacking capacity at some time in the past and not in relation to this specific decision at this specific time. We also found that people were not always given adequate support to be able to have capacity, as it were, through the provision of easy-read information or good support in terms of weighing up decisions. So that was the first concern.

The second concern was about delays in convening best-interests decision meetings, confusion as to who would take the lead in those decisions, poor recording of best-interests decisions, and a lack of understanding of the process to follow if there were disputes about the decision or disagreements as to what the decision should be.

The third issue was that we uncovered considerable confusion about the definition of serious medical treatment and what that means in practice. It was noted that the code of practice accompanying the Mental Capacity Act only advises on medical treatments and not invasive investigations. So for example, if somebody was planned to have an invasive investigation which perhaps involved a general anaesthetic, that was perhaps not always considered to be serious medical treatment, and there was some concern about that. That also led on to inconsistencies about appointing IMCAs, because IMCAs—*independent* medical capacity advocates—are only appointed where there is a serious medical treatment to be decided.

The fourth issue was concerns about what happens to the outcomes of those best-interests decisions, the timeliness, and in fact their implementation at all in some cases. On occasion we found that decisions had been made following due process, but actually they appeared to have been overruled by a number of different considerations, including those of the cost of the service. That was particularly relevant when a best-interests decision had been made to discharge somebody from a hospital into residential care. There were often debates about whether that would need to be specialist (learning disability) care or a generic care environment. Sometimes the best-interests decision was overturned on those apparent cost considerations. We also found that there were administrative delays in implementing the decisions. Sometimes, the views of a third party, which were sometimes crucial to that decision-making process, had not been present at the best-interests meeting and their views then took precedence, and the decision that had been made was sometimes overturned. All

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of that seemed to have taken place without any apparent review as to the impact of that on the individual’s life, either in the short term or the long term.

The confidential inquiry made three recommendations about the Mental Capacity Act. We made three recommendations out of the total of 18 recommendations, so that shows the seriousness with which we took the considerations. The first was that advice needs to be available for professionals 24 hours a day. Within that we suggested a telephone line staffed by experts in the Mental Capacity Act, able to provide telephone advice in a similar way to the way the language line currently works. We also suggested that Mental Capacity Act advisers be employed locally at a senior level in all secondary care establishments and in clusters of GP practices. We also suggested that the national Commissioning Board and clinical commissioning groups must ensure that they have adequate oversight of the appropriate Mental Capacity Act safeguarding arrangements, and that together with regulators they must enforce the Act.

The second recommendation was regarding the definition of serious medical treatment—we feel that that needs to be clarified. The third recommendation was that there does need to be mandatory training and mandatory updates about the Mental Capacity Act for any health and social care staff who are involved in delivering care. We found that there was considerable variation in what people were including in training packages. In that respect we have suggested an approved e-learning package which, supplemented with individual applied training in practice, makes it much more relevant to individuals in the capacity in which they are working. We felt that that needs to be monitored by the national Commissioning Board and clinical commissioning groups and reflected in contracts with service providers.

Q57 The Chairman: Thank you. Dr Flynn?

Dr Margaret Flynn: In relation to Winterbourne View hospital, the independent hospital in south Gloucestershire, the basis on which four out of 51 patients were detained at the hospital is really not clear. You may be aware that a serious case review is a voluntary process, and irrespective of the best efforts of myself and Vic Citarella, we were not able to establish under what power local authorities purported to act as they placed people—at least four patients—at this hospital. We can confirm that these four people were objectively confined and that visiting to all patients at this hospital was very conspicuously restricted and became more so over time. The distress arising from the care regime within the hospital and that which was imposed, including the administration of medication and the use of physical restraint, was not apparently subject to any supervision. It does not appear from any of the documentation that we have seen that this was ever scrutinised or subject to review.

The majority of patients at the hospital were detained under the mental health legislation, and this should have been a fully regulated environment. There are, as you know, multiple layers of safeguards built into the Mental Health Act. However, nearest relatives, IMHAs, hospital managers, and second opinion doctors for example—really, none of those had any impact on the day-to-day circumstances of all patients at this hospital.

It does not appear that commissioners responsible for placing patients in this hospital were instrumental in requesting reviews that perhaps coincided with visits from the First-tier review Tribunal. The hospital took responsibility for hosting reviews; given that patients were sourced from throughout England and Wales, the likelihood of staff from patients’
localities of origin being able to contribute at short notice was much reduced. So the hospital effectively had total control over patients at this hospital.

One of the parallel reviews undertaken by NHS South of England noted that they did not see enough evidence to suggest that the legal status of informal patients was being reviewed in a systematic manner. Their review highlighted concerns that these patients had potentially been deprived of their liberty. Given that my colleague and I could find no further information, we have to share that view, that patients were indeed deprived of their liberty.

We have gone on to recommend that commissioners, before they embark on remote commissioning, or perhaps as we described it, place-hunting, should think very hard about what they are seeking, with and on behalf of adults with learning disabilities and autism. They should be instrumental in ensuring that they lead reviews and that for adults who have to be detained those periods of detention are for time-limited periods.

It does seem to us that, as the Care Quality Commission has confirmed, there is a belief that some adults with learning disabilities and autism and some with behaviours that challenge require perpetual assessment and treatment. This is not the case, any more than it would be the case to suggest that someone who has chronic health problems should be in hospital for the remainder of their life.

Q58 Baroness McIntosh of Hudnall: I will ask a question that may appear very naive, but which is a matter of fact. As a result of the investigations that you did and other inquiries into what happened at Winterbourne View there were a number of criminal prosecutions. I was just wondering whether you know whether failure to comply with the provisions of the Mental Capacity Act was in any way part of the prosecutions that were brought, or whether they were all to do with, for example, assault.

Dr Margaret Flynn: They all arose from the mental health legislation, with nothing relating to the mental capacity legislation. The Crown Prosecution Service position was that the capacity status of patients at the hospital was not known. 103

Baroness McIntosh of Hudnall: Do you have a view about that?

Dr Margaret Flynn: I suppose I share concern and disappointment that such fabulous legislation really had no impact whatever on the circumstances of the 51 former patients at Winterbourne View hospital or even when they attended Accident and Emergency services.

The Chairman: Baroness Shephard.

Baroness Shephard of Northwold: No, thank you—but it is extremely interesting.

103 Dr Flynn added after the evidence session the following information: The CPS spoke of a “Disability Hate Crime” immediately after the trial.
Dr Pauline Heslop (CIPOLD) and Dr Margaret Flynn – Oral evidence (QQ 56 – 73)

Q59 Baroness Browning: I want to ask a question, particularly for Dr Heslop, on the report you co-authored on adults with learning disabilities and their vulnerability and premature deaths. I will look at one aspect, although it is a comprehensive report. It says in your report that, “GP referrals commonly did not mention learning disabilities, and hospital ‘flagging’ systems to identify people with learning disabilities who needed reasonable adjustments”. That is one example, perhaps a very practical example, of something that should be put in place, and one would expect it to be there. Could you just talk about those types of issues, which seem so obvious but which are not happening? Could you also balance that with some of the areas where in your report you thought that there was very good practice?

Dr Pauline Heslop: In terms of good practice, we did find some examples, but it was not good practice throughout the whole of the patient experience. The good practice might have come from one or two individuals involved with that patient, who brought the situation around to following the Mental Capacity Act as it should be implemented. Let me give you an example of that. I have anonymised these names to protect confidentiality. I will describe the case of Brenda.

When Brenda was admitted to hospital her notes on admission described her as—this is in inverted commas—“mute, aphasic and having learning disabilities”. A plan was made to stop any treatment for her and to transfer her back to her nursing home for what was written in her notes as “TLC”. We commonly understand that as “tender loving care”; in other words, no treatment was being offered and she was being placed on an end-of-life pathway. Her nursing home manager disagreed with that, and advocated very effectively that the correct procedure in making that decision had not been followed. She also involved the GP, who also disagreed with that decision. They insisted on the Mental Capacity Act being followed and a best-interests meeting was held to discuss the case that afternoon. As a result of the best-interests procedure being followed, active treatment was resumed for Brenda. She significantly improved within 48 hours, was discharged from hospital two or three weeks later, and she lived for another year, having very good quality of life, then died peacefully in her nursing home a year later. That was quite a typical example where there was one particular individual who knew what the process should be and was able to advocate effectively for that person.

I will give you another example, of Stanley. Stanley had a number of health conditions, progressive frailty from old age, and significant weight loss. Eating had become a real ordeal for him; he was becoming exhausted by eating and was losing a lot of weight. An IMCA was appointed to be involved in the decision-making process about whether his weight loss should be investigated and whether he should have a procedure to put a tube into his tummy to feed him through. The IMCA convened a series of best-interests meetings with various individuals and made sure that all the relevant information was being collected and considered. At the final decision-making meeting it was agreed that it would be in his best interests to have the gastrostomy tube inserted. The consultant who was to undertake the procedure disagreed with the best-interests decision and refused to undertake the procedure. The IMCA was confident enough to challenge the consultant’s decision. She fought for a second opinion for Stanley, and another consultant who she consulted agreed to undertake the procedure. The procedure was done, but there were post-operative complications and the tube came out. The IMCA remained involved in that case, and convened another best-interests meeting about whether it would be in Stanley’s best-interests to reinsert the tube. That decided that it should be reinserted, and it was, and again
Stanley carried on and lived with a much better quality of life for the next 12 months. There you have two examples where there is really effective advocacy for an individual, and that is what has tailored their care and made the Mental Capacity Act effective for them.

Q60 Baroness Browning: Thank you. Can I just ask a supplementary to that? I will phrase this as delicately as I can. There are many people with learning disabilities and people on the autistic spectrum who may not be classified as learning disabled people, who I see that on your list of requirements would be subject to an annual check-up routine—a medical check-up by a GP. How useful is that annual check-up, in terms of not just checking weight, blood pressure, the usual things, but in advocating for the person they are seeing? The reason I am asking is because I am a little nervous that we have GPs who are now seeing people on an annual basis; I am really asking whether they are asking the right questions at that annual review, if they do not see the patient for any other reason in between, to be a reliable advocate for that patient.

Dr Pauline Heslop: We found considerable variability in the quality of annual health checks for individuals with learning disabilities. Some of that may be a question of poor documentation; we do not know because if it is not documented, in our eyes it did not happen. We also saw evidence of a comprehensive health check but actually there was no follow-on after that health check, so no health action plan was designed that would help a person understand their health and take forward the actions that needed to happen following that annual health check. So Annual health Checks did seem to be little isolated incidents in the lives of an individual that were not really threaded through the rest of the year for that individual.

We did find some people where new health conditions were identified in their health check, but during the health check, in relation to the Mental Capacity Act, we did not find any real evidence of assessments of capacity and thinking about proactive planning for an individual, such as what an individual might need within the next year and setting up systems to be able to plan support for that. It seemed very much to be in the moment.

The Chairman: Dr Flynn, I think that the initial question was addressed to both of you. Could you give us any examples of good practice that you have found?

Dr Margaret Flynn: Alas, no! We would struggle to do so from the documents that were made available. I do know that in the very early days of the history of Winterbourne View hospital families spoke positively of the service, and that was associated with the period when there was a registered manager on site and staff appeared to be supervised. But once the manager left and others assumed the role, and there was even a period when there was no manager, practice seriously drifted and became dangerous.

Q61 Lord Patel of Bradford: Dr Flynn, if I may I will take you back to Winterbourne View and the failings there, including the failure to apply the deprivation of liberty safeguards and this tendency to believe staff over patients constantly. Would you say that these were specific to Winterbourne View, or are there general lessons that have been learnt about the Mental Capacity Act and the deprivation of liberty safeguards?

Dr Margaret Flynn: I gather from conversations with relatives who have experience of assessment and treatment services elsewhere in the country that there are enormous concerns about the safety of their relatives when they are detained. In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Lord Patel of Bradford: Detained under the Mental Health Act?

Dr Margaret Flynn: Detained under the Mental Health Act, yes. It is very clear that patients at Winterbourne View hospital were scandalously silenced. I can confirm that, not merely by the fact that the police found written complaints in an office drawer that had been drafted by patients that had not been addressed, and neither were the concerns of families addressed. The very typical response to the concerns of families from staff at the hospital was, “Well, your daughter/son would say that because she doesn’t want to be here. That is what happens—that is why they are here”. So they had no voice. On the issue of advocacy—more generic advocacy—some patients did not appear to have access to anybody. On the one occasion when we know that two patients were able to leave the facility to contribute to a Castlebeck-hosted event—Castlebeck was the owner of the hospital—they did disclose that they were troubled by a member of staff, and they were told to be quiet because their observations were inappropriate. So there was not just no advocacy but a misunderstanding of the purpose of advocacy.

I am convinced that people desperately need independent assistance outwith the hospitals. Winterbourne View Hospital mediated access to advocacy; patients had to go through one of the nurses, and if patients were troubled and distressed they were unlikely to approach nurses who had been known to stand back and observe some of the most egregious abuses that were captured on the TV. I have to suspect that that happens elsewhere, because the work of the CQC has not given us any confidence that these places are safe, or indeed that people’s physical healthcare is given the priority that it very much requires.

Lord Patel of Bradford: In terms of the 51 patients, you said that four were detained under the Mental Health Act.

Dr Margaret Flynn: No; for four, we have no idea under what powers local authorities purported to act as they placed patients at this hospital. Three-quarters of patients were detained under the Mental Health Act.

Lord Patel of Bradford: Therefore the Care Quality Commission would have been visiting in theory and interviewing the patients under the Mental Health Act.

Dr Margaret Flynn: Yes.

Lord Patel of Bradford: In private.

Dr Margaret Flynn: Yes.

Lord Patel of Bradford: And was there any evidence that that was happening?

Dr Margaret Flynn: There is very little evidence that such visits uncovered anything that was useful. They identified some improvements that should be made. There were concerns, for example, about the use of restraint, but nobody followed this up, and so no action was taken.

Q62 The Chairman: You mentioned about IMCAs being allocated through the hospital—that you had to go through the hospital to get an advocate. You were suggesting that that
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should be placed outside the hospital regime. How would a patient go about getting access to this outside agency?

**Dr Margaret Flynn**: To my mind there should be very frequent reviews. Patients are in such an atypical environment, their continuing detention has to be credibly challenged so that they are not left there. The observation of the First Tier Review: Mental Health was that there was a sense that people had been abandoned at this hospital. So there should be frequent reviews, and challenges during those and during monitoring meetings undertaken by staff associated with the commissioning of such places. Patients must be offered opportunities to talk about their day-to-day circumstances.

**Baroness Browning**: Could I just ask Dr Flynn: in your report and investigation did you find any evidence that the local authorities placing patients at Winterbourne View had chosen it on the ground of price?

**Baroness McIntosh of Hudnall**: It was not cheap.

**Baroness Browning**: My colleague quite rightly says that it was not cheap, and it was not, but no in-patient care is cheap in this country.

**Dr Margaret Flynn**: No. That is right. It was anything but a bargain basement service. We know that the average weekly fee was £3,500, but we also know that the weekly fee for at least one patient was just a shade under £10,000. It does not appear that the service that she received was vastly different from that of anybody else. In fact, from the 20 case records that we were able to scrutinise—and that is only 20 out of the 51 that included nursing notes and medical notes—it does not appear that people’s day-to-day circumstances involved anything other than being herded into a single room. There was really very little evidence of assessment or indeed treatment. I would struggle to describe what either involved at this hospital.

**Q63 Baroness Barker**: My question was to Dr Heslop about the confidential inquiry. Your report links poor adherence to the Mental Capacity Act to increased vulnerability to premature death. I suppose the question I want to ask you is whether you can see a more clear causal relationship or is it just that institutions that do not implement or properly implement the Mental Capacity Act have generally poor practice? What I am trying to ask is: is the failure to implement the Mental Capacity Act an indicator of further poor practice?

**Dr Pauline Heslop**: I would say no, because we found some examples of very poor and/or very good practice located sometimes within the same ward or in the next-door ward in the same hospital. It did seem to be very much dependent on individuals in that setting rather than embedded in the institution as a whole. We did not find any particular hospitals where it was all excellent practice or all poor practice. It was much more patchy than that.

**Baroness Barker**: It is agreed that the Mental Capacity Act is a great piece of legislation, as it embodies best practice and great principles, but what are the implications of your report for it, given that, as we are being told by people on the ground, it is not being implemented fully?

**Dr Pauline Heslop**: There are two issues, really. One is about the Act not being followed properly and the second is, to a lesser degree, about a lack of clarity in the Act. Let me go in order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
through the first issue first about its not being followed properly. The assumption of capacity is a good starting point, but in our experience it has not always been questioned when it should be questioned. A particular example of that concerns people who are particularly fearful of contact with medical professionals or medical interventions. We found that a substantial minority of people whose deaths we reviewed had had an overriding fear of medical interventions. I would argue that that fear meant that the person did not really have the capacity sometimes to weigh up what was in their best interests, but that often was not questioned and the assumption of capacity was made irrespective of that overriding fear. That is the first issue.

The second issue is that, unless the best-interests process is being followed properly, it would appear that the judgment of one person could determine the life-threatening or life-saving trajectory that has been followed. That judgment has sometimes been made, we know, based on prejudice, a lack of information or a lack of a holistic assessment of the individual.

A third issue is that best-interests decisions for people who are unsupported have been made to put them on an end-of-life care pathway when, in fact, if they had had supportive advocacy, a different decision might have been made. For example, we reviewed the death of one lady who was admitted to hospital for investigations of a condition but was discharged home on an end-of-life pathway before the results of those investigations had been received. That lack of due process in assessing her capacity to be involved in that decision and in following her best interests is of concern. We also found that there were significant delays in following up on best-interests decisions. That, too, was of concern. Could I give you one or two case studies to illustrate some of those points? Would that be helpful?

**Baroness Barker:** Given the time, I wonder whether I could put a question to both of you. **The Chairman:** It would be useful if you maybe submitted in writing the cases studies, as those would help us to understand the points you are making.

**Dr Pauline Heslop:** Perhaps I can add just one more thing, which is about the lack of clarity in the Act. We found that the current link between the Mental Capacity Act and “do not attempt cardiopulmonary resuscitation” orders needs some clarification. We found examples where the decision not to resuscitate an individual had been made in an emergency situation, such as when someone had just arrived in A&E, based on very limited information, but then that decision had not been reviewed. One of the recommendations of the confidential inquiry is to separate out emergency decision-making from non-emergency decision-making, regarding “do not attempt cardiopulmonary resuscitation” decisions. Those non-emergency decisions should be made under the full protection of the Mental Capacity Act in a best-interests decision-making process.

**Q64 Baroness Barker:** The question that I wanted to put to you is one that you may wish to go away and consider, rather than giving us an immediate response. We are trying to get to the bottom of why this legislation, which everybody tells us is so good, is so patchily observed or widely ignored. Given what you have had to say today, this is very much viewed as a piece of legislation that applies to individuals in individual circumstances. The question that I have to ask you is whether you think that the legislation that the Department of Health is about to introduce on corporate responsibility will have an impact on and an interplay with the Mental Capacity Act. Do you think that that could be seized as an
opportunity to make the implementation of this Act more coherent and widespread? That is a big question, which you may want to take away with you.

**Dr Margaret Flynn:** I suppose my only quick observation would be that, throughout the Winterbourne View hospital debacle, there was a clear theme of deference to clinicians and the assumption that nurses were working as clinicians. When Avon and Somerset Police rang the hospital, (as the result of a patient ringing 999 asking for help) they believed that they were dealing with clinicians. We know that that this was not the case. However, that deference prevailed. When people were to be discharged, clinicians were sometimes instrumental in their continuing detention, saying for example, “I think it would be worth while retaining this person for at least a further six months to work on his anxiety”—that is a real case from Winterbourne View hospital. The challenge that is endemic in best-interests assessments was not there—it was completely absent from this institution—and the clinicians were able to take some decisions that, in retrospect, we know to have been massively unhelpful.

**The Chairman:** I think it might be useful for you to have time to reflect on that question and perhaps give us some written evidence, once you have had time to consider it properly.

**Q65 Baroness McIntosh of Hudnall:** There is an inherent tension, which is identified in the guidance, between allowing people to make decisions and ensuring that they are protected from harm that may come to them. The Mental Capacity Act, in attempting to recognise that having capacity is the thing that should be focused on, also therefore accepts that some of the people to whom it applies are very vulnerable and need protection. Could you give us your views about what is the appropriate way to negotiate between those two sometimes apparently conflicting imperatives? Dr Flynn, no doubt some of the people whose cases you reviewed at Winterbourne View were extremely vulnerable but also had capacity.

**Dr Margaret Flynn:** Yes, indeed, that is the case. This can only be done on a case-by-case basis and it can only be realised if the registered manager, proprietors and staff are completely honest and open about events at the hospital. We observed in the “Panorama” broadcast the use of fiction in describing some of the events at the hospital. I cannot help but think that, had there been thorough scrutiny of some of the documentation pertaining to some of the patients, it would have been very clear that there was an extraordinary and excessive use of physical restraint, which no professional asked any questions about. It would also have become very clear that there was an extraordinarily high level of absconding from this hospital. We know that behaviour is extraordinarily eloquent, but the eloquence of that behaviour was never seen for what it was—patients wanted to get out. They were simply returned to the hospital. The hospital did not inform the regulators and did not inform the commissioners of the service. We are highly dependent on the honesty of the hospital itself. This was a small institution; it was remote and inward-looking. It had all the characteristics of a total institution.

**Baroness McIntosh of Hudnall:** But if you turn that round—perhaps, Dr Heslop, you could reflect on this—it is also the case that, in some instances, care has been neglectful on the basis that people had capacity and therefore intervening was not appropriate. That is equally damaging, but from an entirely different starting point.

**Dr Pauline Heslop:** Absolutely. We have reviewed the deaths of some people who were assumed to have capacity but where I do not think any formal assessment was done. They
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were in very vulnerable situations. Two of them died in quite suspicious circumstances, I think. This was really driven by their desire to have particular friends or to engage in particular activities. We need to be much better at assessing capacity. In the code of practice, we need much more sophisticated examples of the thought process that we should go through in assessing capacity. Where there is any doubt about capacity to make a decision, an independent advocate should be appointed to support that decision-making process.

**Dr Margaret Flynn:** I would endorse that. I am concerned that the claim that somebody has capacity is often not evidenced. It seems to me that it is a new substitute for the claim that a person has made a “choice”, as though the is irrevocable, immutable and long-term. I have certainly come across examples of older people who, in 1987 say, were described as having capacity and it was believed that that was still pertinent to 2012, for example.

**Q66 Baroness Andrews:** Can I go back to the contextual issues of the health treatments? You have made several different sorts of references and, Dr Flynn, you have talked about the failure to understand exactly what was meant by serious medical treatment. You have referred to annual checks as being occasional and not followed through and so on. In both your reports, there is an indictment of the failure of the health professionals themselves to actually engage with some of the issues. In Dr Heslop’s report, you talk about 97% of the people you looked at having “had 1 or more long-term or treatable health condition”. In reference to Winterbourne, there was the shocking statement, actually, that in the case files of 20 patients there was a “multiplicity of physical health problems and it is not known whether or not these were treated or” even “monitored”. There seems to me to be a dereliction here which certainly betrays the basic principles of the NHS. My question really is: did you come across cases in that context where you thought that Section 44 of the MCA itself, which deals with abuse, could have been invoked or would have been relevant?

**Dr Margaret Flynn:** What lodges in my memory is reading through the 20 files over a weekend with a GP colleague, and discovering that one male patient had disclosed to a member of staff that he had found a lump in one of his testicles. We could find no subsequent reference to actions taken as a result of that disclosure. There is something truly bizarre about ringing the director of adult social services on a Sunday evening and saying, “Wherever this man is now, he needs urgent medical treatment”, which he did receive and which he very much required. It is astonishing that that happened in a hospital, where we imagine that physical healthcare, minimally, is going to receive the attention that it merits.

I do not know what the procedure was within the hospital when people were unwell. We know that a local GP was on some sort of retainer with the hospital. I do not know how frequently the GP visited or how adequate the visits were, but it is very clear that people were unwell at this hospital and that they were taking enormous quantities of, for example, laxatives and anti-psychotic medication that was not merited by their diagnoses. We know that.

**Baroness Andrews:** May I just ask a follow-up? I cannot remember in your report whether there were recommendations in relation to the health service and the relationship between local GPs and care homes? Did you make general recommendations of that nature?

**Dr Margaret Flynn:** We know that some patients were physically injured as a result of being subject to restraint at Winterbourne View hospital. Some fractured bones, and they in order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
received treatment in local A&E services. We do know that one consultant was extremely concerned that the description of an injury was not consistent with the nature of the injury, but that concern was not fed onwards. It would have been disclosed in any event to the accompanying member of staff, who was unlikely to report directly to either the CQC or the local safeguarding personnel.

**Q67 Baroness Andrews:** In relation to Dr Heslop’s report, you actually made a whole raft of recommendations about improved relationships with the health service. We have referred to DNACPR. You talk about named healthcare co-ordinators, patient-held health records, standardisation of health checks, access to specialist healthcare and specialist learning disability services. You have talked also about the fear of medical intervention, which presumably compounds this situation. Of those recommendations, which do you think actually would be most effective? Who should take the lead? Who should take responsibility?

**Dr Pauline Heslop:** Big question. I guess answering it in relation to your question, or directly in relation to the Mental Capacity Act—I am not quite sure I am answering your question—

**Baroness Andrews:** Ultimately, the MCA.

**Dr Pauline Heslop:** I would say we needed to be much better at identifying who people with learning disabilities are within the health service but, more importantly, we also need to be documenting the reasonable adjustments that they need to be able to access healthcare equitably, and we need to be auditing that the reasonable adjustments are being made. That will start us along the track of thinking about linking that in with the Mental Capacity Act, in terms of good decision-making for individuals once we know that there might be a need for that.

Related to the Mental Capacity Act, we did not find evidence of people setting out to deliberately harm an individual. What we found much more commonly was that judgments were being made about individuals and about the provision of care for those individuals which were not always optimal. They were not always fully recorded, so we could not clearly follow a decision-making trail. There are issues about that sub-optimal care. For example, a doctor watching and waiting just that little bit too long than was reasonable, or concoctions of medication that maybe had not been reviewed in a timely way—neither of the definitions of ill treatment or neglect within the Mental Capacity Act would, I suggest, cover those. But we did find that that general poor practice was a contributory factor to deaths.

**Baroness Andrews:** Could you recommend changes in the code of practice which would address some of this, in the context of looking again at the code?

**Dr Pauline Heslop:** Yes. I can certainly submit written evidence for you and neatly bundle together, if you like, our recommendations for the code of practice, if that would be helpful.

**The Chairman:** That would be very helpful indeed.

**Q68 Baroness Browning:** Could I just ask one quick question of Dr Heslop? In an earlier answer, you made reference to somebody with a learning disability who had inappropriately been put on an end-of-life care pathway? I just wonder whether, in your key...
recommendations, you felt there might be something to be said about people with learning disabilities and end-of-life care pathways? After a lot of pressure from the House of Lords, the Department of Health—I have to say, rather reluctantly, but it is now doing it—is reviewing the Liverpool care pathway, which is chaired by Baroness Neuberger. I did just wonder whether I could use this opportunity to say, if you have evidence of learning disabled people and their experience of the end-of-life care pathway, I think many of us would be very grateful if you would submit it to her inquiry.

Dr Pauline Heslop: One of the recommendations that we did make was that nobody should be put on an end-of-life care pathway without some referral to a palliative care service, as an additional check that that was an appropriate course of action for that person. So I hope that will go some way towards—

Baroness Browning: Thank you. We are very worried about people who have full capacity, let alone people without capacity.

Q69 Baroness Shephard of Northwold: The serious case review into Winterbourne View found that “light touch regulation did not work”. What implications do you think that finding has for regulation of the Act?

Dr Margaret Flynn: It did not work because the hospital was very good as presenting itself as a service that was next to none. Certainly, its documentation was very impressive-looking. We know that, with the binary of compliant or not compliant, it is easy to be regarded as compliant without really scrutinising what is happening on a day-to-day basis. I think we should take heart, however, notwithstanding the circumstances of the Care Quality Commission, that once the shockwaves arising from the broadcast were over, the Care Quality Commission, spent about four days there. There were inspectors who spent time with patients, looked at records and, on the basis of that, were able to make the sorts of decisions that we would have hoped they could have made before the undercover filming.

It is not enough to check whether or not there are policies and things in place—the right number of bedrooms for example. That is only a very small part of the story. We have to spend time with people, and we have to observe—make observations about what is happening and how people spend their day-to-day lives. We have to learn something about people’s biographies, not merely rely on information arising from their diagnoses and their case records. This was a hospital that promoted itself as taking anybody—the sort of person that nobody else would take, people who were “too difficult” for their local services to support. What we did find was that that was absolutely not the case. That is not to say that there were not some very troubled people who were at this hospital, but their histories attest to the pain arising from events in their lives, including being sexually assaulted in places where they should have been most safe. I do not know that information about people’s biographies was ever taken into account by any of the practitioners at the hospital.

It really would not have taken very much for someone to spend a little bit of time focusing on one or two patients and trying to understand something of their circumstances. We know that there is a problem when we ask people, “How are you?”—particularly when strangers ask somebody, “How are you?”—and we are very likely to say we are fine, even though we might be extremely scared because the person who might be sitting alongside me is responsible for causing my pain. The Care Quality Commission and other regulators have to think very differently about working with people who are in conditions of detention.

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which is why we suggested that there should be something akin to Her Majesty’s Inspectorate of Prisons—something much more ruthless than a fairly gentle, “This is when we’re coming. Put the kettle on.”

Lord Patel of Bradford: Because the patients were detained under the Mental Health Act, mental health commissioners from the Care Quality Commission have a duty to actually meet patients in private and do more than say, “How are you?” and actually physically pursue having a discussion and follow up. Clearly, that was lacking here. That is their role under the law as it is. That is obviously what is not happening. I think it is a point that we need to keep coming back to. Anybody who is detained should be interviewed and met and have private discussions. The bulk of the information arises from that meeting, which clearly was not an issue here.

Dr Margaret Flynn: That is right. I think, too, really valuable information such as patients going to A&E because they have been injured as a result of physical restraint is incredibly important, yet the commissioners were not consistently told about it. Neither was the CQC. The Health and Safety Executive took the view that, on the occasions they were informed of patients’ injuries, they were not serious enough for them to undertake any investigation.

The Chairman: Dr Heslop, I think the question was addressed to both of you. If you have anything to add to that—

Dr Pauline Heslop: I can add in a very small way. Obviously, the confidential inquiry reviewed the individual circumstances of people’s deaths. We did not review services, as it were. However, we did pick up on a number of issues that we would have expected a review of that service to have identified and required addressing—for example, a full assessment of a person’s needs, that a person was living in inadequate or inappropriate accommodation, poor record-keeping. In all those cases, the light-touch approach clearly does not seem to have worked.

Q70 The Chairman: Baroness Hollins cannot be here today, but she has asked me to ask both of you a question. What experience do either or both of you have of how the Care Quality Commission is using the Mental Capacity Act in its inspections of hospitals such as Winterbourne View, or even acute hospitals, in order to ensure that people with learning disabilities are being included appropriately in decision-making?

Dr Margaret Flynn: I believe that the Care Quality Commission are currently piloting work on interviews with patients with learning disabilities. I have been party to a meeting about the interview schedule, and I did have some concerns about asking 100 yes/no questions of adults with learning disabilities. We know that there is a tendency to acquiesce when people are uncertain and maybe have limited educational experience. I have expressed my concern. I understand that the schedule is being deployed with very mixed, if not terribly happy, results. I think we can do better than this. I would not want us to lose the impetus from Winterbourne View hospital to do something so very much better. The Care Quality Commission themselves have shown that they can field individuals, including experts by experience, and spend time with people and learn more about a service than their previous light-touch “Tell us how you’re doing” approach of hospital managers and staff. I have

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Concerns about the current approach. I do think there should be professionals who are part of that process, as well as experts by experience. That would necessarily include clinicians, not least of all because this is a population that is highly vulnerable to being overmedicated and to being subject to unspeakable restraint.

The Chairman: Dr Heslop?

Dr Pauline Heslop: The confidential inquiry did not find any evidence of Care Quality Commission reviews in terms of the healthcare of people with learning disabilities whose deaths we reviewed, so I am unable to really add very much to that and I would not want to say anything extra.

Q71 Baroness McIntosh of Hudnall: You both identified in your different reports the importance of advocacy, and you have already made that point in earlier answers. Do you want to amplify what you have said already on the subject of the importance of access to advocacy? Tell us, if you will, whether you think changes are necessary in the way that advocacy services are provided, for example.

Dr Pauline Heslop: Generally, we found the involvement of IMCAs to be very positive for the individuals concerned. They provided very useful protection for individuals, but where we did find difficulty was: in the definition of serious medical treatment and the triggering of an IMCA involvement regarding that; people being aware that an IMCA needed to be appointed—there was some confusion about that—and decision-makers relying on the views of sometimes very distant family members who maybe had not been in contact with the individual for some years, when actually the appointment of an IMCA might have been more appropriate and provided better protection for the individual in that circumstance.

Baroness McIntosh of Hudnall: But more expensive, possibly? Would that be fair?

Dr Pauline Heslop: Yes, of course. A major concern that we had was that IMCAs were only involved in a decision-specific way, and that very often there was no follow-up mechanism at the end of a decision being made to ascertain whether that decision had been carried out, whether there were any problems, whether it was the right decision and whether another decision needed to be made. I would suggest that we need to give consideration to more ongoing involvement by advocates with people, rather than just specific involvement for a specific decision.

Baroness Andrews: I was very struck by the evidence in your report, Dr Flynn, about the tragedy of the families who felt completely desperate that no one was listening to them, even when they had powerful evidence. What sort of advocacy could be provided which would be effective for families?

Dr Margaret Flynn: They were ill served by the fact that there was no registered manager at Winterbourne View hospital for at least two years. There should have been a registered manager. There was an acting manager there and the consensus was that, in that role, that person was entirely ineffectual. There has to be a manager who is accountable and responsible, who sets the tone and takes responsibility for supervision and ensuring that a service delivers all that it undertakes to deliver. In the absence of that, I think I would want tenacious, persistent and very competent professional advocates—people who would not be
fazed by clinicians, who would not be unduly deferential, and who would ask the searching questions that I would have expected, perhaps naively, NHS commissioners to be asking.

**Baroness Andrews:** I was just thinking what role the health and well-being boards might have in taking up some of those issues. But do you think the IMCA could be adopted or modified?

**Dr Margaret Flynn:** Rather as my colleague has suggested, yes, I think they should be, but we want them to go beyond specific decisions and to look at somebody’s circumstances in the round, otherwise we might lose sight of the inventive and protesting voices of patients which may otherwise be lost in a hospital setting.

**Q72 Lord Swinfen:** Dr Heslop, the confidential inquiry report notes failures in the determination both of capacity and best interests, and proposes increased provision of training to remedy these issues. Were there particular areas of practice or types of practitioner—doctors, nurses, care workers, social workers—where understanding of the Mental Capacity Act was particularly good or particularly bad? An additional question for both of you at the end of that is: what else could be done, in addition to training, that would improve adherence to the Mental Capacity Act by individual members of staff?

**Dr Pauline Heslop:** Starting with types of practitioners, we found that there was particularly good knowledge about the Mental Capacity Act in specialist learning disability nurses, both in the hospitals and in the communities, and that their involvement had been instrumental in ensuring that proper procedures were followed for patients at times where they were involved. We found some knowledge about the Mental Capacity Act amongst care home managers, but the finer details of that were sometimes missing, and particularly missing among front-line junior care staff. We did identify some tensions between family carers not understanding the Mental Capacity Act and practitioners who were involved in decision-making about their family members. That is certainly an area where we need to improve knowledge. However, we found generally poor knowledge, I am afraid to say, amongst non-learning-disability-specific hospital staff, at primary and secondary level—so amongst GPs and medical and nursing staff. I think that that probably is the key group to target, in terms of targeting training—not just new entrants to the medical and nursing professions, but for established consultants who might still work in a model of healthcare that is rather more directive than collaborative with the patient.

In terms of areas of practice, we found that where there was a decision about moving a person maybe from a hospital into a care home, it did seem to be recognised that the Mental Capacity Act needed to be followed in those circumstances. There was much less adherence to and understanding of the Mental Capacity Act regarding any sort of medical decisions, including, as I have already said, about understanding what serious medical treatment is and when the protection of the Mental Capacity Act should be afforded.

What else could be done in addition to training? The way in which we conducted the confidential inquiry was to bring professionals together to reflect on the sequence of events that led to a person’s death. Almost unanimously, professionals found that a very positive experience. They saw where their little bit of the jigsaw fitted into the rest of the jigsaw, if you like, and learnt from each other in that environment. Certainly, it raised awareness about the Mental Capacity Act amongst professionals who should have known about the

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Mental Capacity Act beforehand. So that reflective practice—getting involved in case reviews in a very non-judgmental way in some ways—was experienced as a learning opportunity.

I think we need more sophisticated case examples in the code of practice, and I am happy to submit some written evidence about that. We have already talked about a 24-hour helpline to provide advice and lead practitioners in hospitals and clusters of GP practices. We need to use patient safety reporting mechanisms a bit more. My own view is that there is not anyone on the ground scrutinising adherence to the Mental Capacity Act. There is not that knowledge base; there is not the confidence to challenge senior consultants maybe, for example, if the processes are not being followed—apart from our experiences with learning disability liaison nurses, I must say. So we do need to strengthen that protection there. Some of the case law coming through at the moment might emphasise its importance, and I think we need to share that information more widely. We have got much less evidence about this from the confidential inquiry – but we did find some confusion about the applicability of DOLS—deprivation of liberty safeguards—and we need clarification of that, both in the legislation and in the code of practice.

Dr Margaret Flynn: I would only endorse that. As you will have gathered, the mental capacity legislation appeared to have little impact at Winterbourne View hospital. However, no clinician is going to say that they act in anything other than the best interests of their patients, and it does seem to me that clinicians at this hospital were not subject to the challenge. Rather, they received the deference of people who could and should have been challenging. I suppose one way of exploring this would be to ask the Winterbourne View hospitals of this world, “What have you done in the last 12 months as a result of the mental capacity legislation? Give us some specific examples pertaining to patients who are detained and patients who are informal. Give us some examples.” Arguably that would uncover the limited impact of the legislation in services for very vulnerable people.

Q73 Baroness McIntosh of Hudnall: Could I just pick up, Dr Heslop, what you said about specialist learning disability nurses? To put it very simply, are there enough of them? We had the impression from one of our earlier witnesses, who is a consultant in that field, that there were not very many. Indeed, I think he told us that he was the only consultant in the field in the country. Given that the people that you met who were in that group appeared to be the best informed and the best at interpreting and implementing the Act, should there be more of them? Are they routinely part of every hospital’s cohort or not?

Dr Pauline Heslop: They are not routinely employed in every hospital. The confidential inquiry covered five acute hospitals, and there were learning disability liaison nurses in three of those. In the other two hospitals, there was a lead nurse for learning disabilities who also had other responsibilities to her role—so, for example, she was the lead role for dementia and for safeguarding. That obviously eats into her time. I would strongly advocate that there should be at least one—and probably more—learning disability liaison nurses in each hospital. They afford good protection for people with learning disabilities. However, they only afford protection for people with learning disabilities, and the Mental Capacity Act obviously goes wider than that. I do not think we should rely on just one professional group to be flying the Mental Capacity Act flag; it is everyone’s responsibility.

The Chairman: Thank you very much indeed for a very interesting session. We have all derived a lot of information from your evidence and are grateful to you for coming. I would like to emphasise that we have put the call out for evidence. I know you have said that you

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will be submitting additional pieces of evidence in response to matters that have arisen today but, if there are any other issues in the call for evidence that you feel you wish to comment on, it would be of tremendous assistance to us. Thank you very much indeed for your time.

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Dr Pauline Heslop (CIPOLD) – Written evidence

Thank you for this opportunity to supplement the oral evidence we supplied to the Committee on 2nd July 2013 with this written evidence. Our evidence is based on the findings of the Confidential Inquiry into premature deaths of people with learning disabilities (CI).

1.0 The CI reviewed the deaths of 247 people with learning disabilities aged 4 years and above who had died during the two year period June 2010 – May 2012 inclusive.

1.1 Here, we would like to provide supplementary information in relation to three particular issues as discussed with the Committee:

• To provide case examples of the relationship between lack of adherence to the Mental Capacity Act and premature deaths of people with learning disabilities
• Amendments that we believe could usefully be made to the Mental Capacity Act Code of Practice
• Reflections about whether the proposed legislation about corporate responsibility would impact on adherence to the Mental Capacity Act.

Case examples of the relationship between lack of adherence to the Mental Capacity Act and premature deaths of people with learning disabilities

2.0 The Six Lives Progress Report (http://www.ombudsman.org.uk/improving-public-service/reports-and-consultations/reports/health/six-lives-the-provision-of-public-services-to-people-with-learning-disabilities) stated that failures by healthcare staff to comply with the Mental Capacity Act and its Code of Practice were among the most worrying evidence received. The Confidential Inquiry review of deaths has also identified considerable concerns about adherence to the Mental Capacity Act, and the differences in the understanding and implementation of each of its principles on the part of some health and social care professionals.

2.1 Sabina: A 48 year old woman with severe learning disabilities, Tuberous Sclerosis and autism. She lived in a residential care home and her family hadn’t visited for over two years but kept in limited phone contact (once or twice a year) with the home. Her behaviour was frequently described by her carers as ‘difficult’, with spitting, screaming and aggression. She had a considerable fear of medical interventions and was described by her GP as being ‘almost impossible to examine’.

She developed left-sided swelling of her arm and leg and her GP was asked to visit the care home. Unsuccessful attempts to examine the swelling were made on several occasions over a two-week period by two GPs. Eventually, one GP was able to conduct a limited examination of her left arm and no further action was proposed.

She then developed a left-sided facial droop. A Community Care Review identified that as she lacked capacity to make a decision about her own health needs a Best Interests meeting should be held following the Mental Capacity Act. However the GP felt that no further examination or investigation of her symptoms was required, so the meeting did not take place. Over the succeeding months her carers registered the patient with a different GP and

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a Best Interests meeting was planned to discuss whether she should have an MRI scan to investigate her symptoms and if so, the likely need for sedation and restraint to admit her to hospital. Almost a year after her symptoms first appeared, and before the Best Interests meeting was convened, Sabina died.

2.2 The link between lack of adherence to the Mental Capacity Act and premature death in Sabina’s case:

- Unless the MCA best interests process is being followed, the judgement of one person can determine the life threatening (or life saving) course of action for a person - but that judgement may be made based on prejudice, a lack of information about the person, or a lack of viewing the person holistically.
- Delays in convening Best Interests meetings can be fatal
- There appears to be confusion as to when the Mental Capacity Act should be applied (for treatment or investigations?)
- The lack of effective professional advocacy for a person early on in the process (ie as soon as a person is assessed to be without capacity to make a particular decision) can disadvantage a person
- There appears to be confusion as to what process to follow when there are disagreements about the process or regarding the decision itself.

2.3 Fiona: Fiona became acutely unwell with abdominal pains but refused to go to hospital as advised by her GP. The attending GP did not assess her capacity regarding this decision, but relied on a previous mental capacity assessment when she was less critically ill and had refused to go to hospital. The attending paramedics also decided that they were powerless to act – again without reassessing her capacity on this occasion for this decision.

The following day it was apparent that Fiona needed urgent life-saving medical attention, but she was still refusing to go to hospital. It was not until she collapsed several hours later that she was taken to hospital and received surgical treatment, but she did not recover and died two weeks later.

2.4 The link between lack of adherence to the Mental Capacity Act and premature death in Fiona’s case:

- The presumption of capacity is a good starting point, but should be questioned more than it is
- The assessment of capacity should be time- and decision-specific, but there appears to be confusion about this
- A person’s over-riding fear of medical intervention is likely to mean that they are unable to weigh up the advantages and disadvantages of investigation and treatment, and a test of capacity should be undertaken in this respect.

2.5 Millicent: Millicent had mild – moderate learning disabilities and was able to convey her likes and dislikes. She had only sporadic and infrequent contact with her siblings. Mildred was diagnosed with gallstones, including one obstructing her common bile duct which was causing pain, vomiting and jaundice. She was not considered to be a good anaesthetic risk for an investigative and therapeutic procedure that would require an anaesthetic, and was discharged home from hospital while her GP sought further support for her. Millicent’s condition deteriorated. There was another attempt to have her admitted to hospital but notes record that the decision not to admit Millicent was influenced by the fact that the local
accident and emergency department was full and that if she were admitted, she may be waiting on a trolley for many hours. Following discussion with the staff at her care home, the GP made the decision to keep Millicent at home where she died the following day.

At no time was Millicent’s capacity assessed, nor was there a formally considered and documented Best Interest process involving the multidisciplinary team, her family or an IMCA, or other people who knew her well.

2.6 The link between lack of adherence to the Mental Capacity Act and premature death in Millicent’s case:

- Millicent’s views about her own care and treatment were not considered
- The decision not to treat her was taken by a small number of people without considering the views of other professionals, her family or an advocate.

Amendments that we believe could usefully be made to the Code of Practice

3.0 In general, the Mental Capacity Act Code of Practice has been considered to be helpful to practitioners. However, the Code of Practice was written before the Mental Capacity Act came into force, and could now be usefully amended to provide more sophisticated case examples that are more firmly rooted in practice. Please note that we are not suggesting that the whole of the Code of Practice is rewritten. There are four key areas that the Confidential Inquiry considered could helpfully be amended:

3.1 The Code of Practice advises on medical treatments, not invasive investigations, and more specific recommendations and guidance on invasive investigations would be welcome. In particular, we recommend that the Code of Practice should contain a clear definition of what constitutes ‘serious medical treatment’, and provide relevant, illustrative, practice-based examples and case studies that more subtly illuminate what is meant by ‘serious medical treatment’. The Confidential Inquiry suggested that the definition of serious medical treatment should be clarified to include:

- decisions taken when any illness is newly diagnosed
- health screening
- any decisions not to treat or investigate symptoms
- decisions about ceilings of treatment
- non-emergency DNACPR decisions
- any major decision that may be life-changing.

In its response to the Confidential Inquiry, The Department of Health agrees that this is an important issue and in its response to the Confidential Inquiry has stated that it has approached NHS England and the Learning Disability Professional Senate to consider how to fully address this.

3.2 The current link between the MCA and Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) guidelines needs some clarification. During the course of the Confidential Inquiry we found examples where the decision not to resuscitate a person was sometimes made in an emergency based on limited information, but if the person recovered, that decision was not then reviewed. In addition, we had suspicions that DNACPR orders were sometimes being used to rationalise ITU use. The Confidential Inquiry has

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recommended that DNACPR Guidelines are reviewed, and that the decision-making processes for emergency and non-emergency decisions should be separated. All non-emergency decisions should be made with regards to the Mental Capacity Act and the Code of Practice needs to be clearer in this respect.

3.3 The Confidential Inquiry identified an issue about how much weight decision-makers were placing on the views of very distant family members who may not have been in contact with the key individual for a considerable length of time and who were therefore unlikely to be in a position to fully understand the individual’s views. We found evidence that the views of distant family members were sometimes prioritised over those of care staff far more familiar with the person and their wishes. There did seem to be an interpretation of the Mental Capacity Act by some professionals that family views (no matter how removed that person might be from the individual) should ‘trump’ those of paid carers who knew the person well and it would be prudent for the Code of Practice to clarify this.

3.4 Of particular concern in the Confidential Inquiry was how professionals were assessing (or not fully assessing) the capacity of an individual. We suggest that the Code of Practice needs to provide clarity about assessing capacity, with sophisticated case examples to illustrate a variety of scenarios.

Reflections about whether the proposed legislation about corporate responsibility would impact on adherence to the Mental Capacity Act.

4.0 The proposed legislation about whether Directors should be held personally and criminally responsible for abuse or neglect of patients on their watch is unlikely, we suggest, to impact on adherence to the Mental Capacity Act, although it would be an entirely appropriate measure in other respects. The reason for our pessimism regarding its impact on the Mental Capacity Act is because of the Act’s particular definitions of ill-treatment (more than trivial ill-treatment, and covers both deliberate acts of ill-treatment and also those acts reckless as to whether there is ill-treatment) and neglect (wilful neglect requires a serious departure from the required standards of treatment and usually requires that a person has deliberately failed to carry out an act that they were aware they were under a duty to perform).

4.1 The Confidential Inquiry didn’t find any evidence of people setting out to deliberately harm an individual. What it did find was that contributory factors to deaths included particular judgements being made about the provision of care and treatment for people with learning disabilities which were not always optimal, poor recording of the rationale and process of decision-making, and sub-optimal care or poor practice e.g. an individual being on inappropriate medication, or a practitioner ‘watching and waiting’ a little too long. The definitions of ill-treatment or wilful neglect in the MCA are unlikely to be applicable to circumstances such as these, suggesting that prosecutions for corporate responsibility would be difficult to pursue.

We would like to thank the Select Committee for the opportunity to share our concerns about understanding of, and adherence to, the Mental Capacity Act by health and care professionals.
Dr Pauline Heslop (CIPOLD) – Written evidence

Dr Pauline Heslop, on behalf of the team conducting the Confidential Inquiry into premature deaths of people with learning disabilities

27 August 2013

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
1. **Scope**

1.1 This submission is confined to questions 16 and 17 in the Committee's call for evidence:

   - Are the safeguards in the Deprivation of Liberty Safeguards (DoLS) adequate?
   - Are the processes for authorisation, review and challenge of DoLS sufficiently clear, accessible and timely?

1.2 It is clear that there is considerable and continuing uncertainty about what it means to be deprived of liberty. That uncertainty extends into perhaps surprising areas. When the Institute of Psychiatry gave a series of scenarios to "six eminent barristers and solicitors with expertise in mental health law" and asked whether those scenarios disclosed deprivation of liberty, the consistency of agreement between the lawyers was “no better than chance". 104

2. **Liberty**

2.1 Even before deprivation of liberty, the DoLS have no clear conception of what liberty means.

2.2 The Mental Capacity Act 2005 (MCA) tells us that deprivation of liberty means the same as in Article 5(1) of the European Convention on Human Rights (ECHR); 105 and in that regard, the European Court of Human Rights (ECtHR) has said that liberty “is individual liberty in the classic sense”. 106

2.3 We proceed as if this definition is uncontested; as if this is what liberty must mean and all it can mean. In fact, there are other theories of liberty.

2.4 One of those is the republican theory of liberty, which, though it is over 2,000 years old, has survived into our age and still seems to have something significant to say.

2.5 If it is applied to the DoLS, the republican theory produces striking results: 107

   (a) It says that a person is deprived of liberty not only where there is actual interference with him, but also where there is the possibility of such interference; where he is actually locked in a room, but also where his relationship with others

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105 MCA, section 64(5).

106 Engel v The Netherlands (no 1) [1976] 1 EHRR 647, at paragraph 58.


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is such that he could be locked in a room. At a stroke, that removes the problems of definition created by recent decisions of the Court of Appeal.\textsuperscript{108} We no longer have to think so carefully about the constraints actually imposed upon an individual: they become only as relevant as the constraints that might be imposed, and that is a very different thing.

(b) The republican theory therefore makes it easier to say that someone is deprived of liberty; to declare of a given situation that it amounts to deprivation of liberty.

c) Against that, we have to set the second characteristic of the republican theory: provided there is law worthy of the name, any interference will not amount to deprivation of liberty. Thus, the mere existence of the DoLS might mean that a person is not deprived of liberty (and, therefore, that the DoLS need not be used).

2.6 In effect, adoption of the republican theory of liberty both creates a significant problem in the context of the DoLS and simultaneously ensures that, entirely because of the DoLS, that problem is solved, and that other problems that bedevil the DoLS can be solved as well.

3. A scale

3.1 When it comes to definitions, a further difficulty is created by the Code of Practice to the DoLS.\textsuperscript{109}

3.2 The code suggests that when deciding whether someone is deprived of liberty, “It may ... be helpful to envisage a scale, which moves from ‘restraint’ or ‘restriction’ to ‘deprivation of liberty’”\textsuperscript{110}

3.3 There are several problems with this scale approach:

(a) How can we know precisely how to populate our scale? Logically, there must be a number of points on the scale, each representing a particular intervention in a person’s life, from those constituting only a slight diminution of liberty to those that approach deprivation of liberty. But the number of possible interventions is not fixed; new ones might be made from time to time and any of them might be modified in numberless ways. Where on the scale are the various interventions to be placed, and, crucially, where in relation to each other? Is putting someone in a low chair closer to deprivation of liberty than to liberty? How does it stand in relation to shepherding someone away from an open door?

\textsuperscript{108} See, for example: P and Q v Surrey County Council and others (2011) EWCA Civ 190; Cheshire West and Chester Council v P (2011) EWCA Civ 1257.

\textsuperscript{109} Department of Health, 2008, Deprivation of Liberty Safeguards: Code of Practice.

\textsuperscript{110} Ibid, paragraph 2.2.

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(b) If all we have is the scale, on which single interventions are placed side-by-side, how are we to take account of the aggregate of two or more of them? How, in fact, are we to aggregate them at all, and even if we succeed in doing so, where, precisely, are we to place the aggregated interventions? Is shepherding someone away from an open door closer to deprivation of liberty than putting him on a low chair and reducing the length of his visits from friends? How will the scale help us decide?

(c) All the scale does is display subtle progressions between two points, so, arguably, it cannot help us with the DoLS. The knowledge that the use of ‘baffle locks’ tends rather more to the right-hand end of the scale than the left is worthless. When what we most require is a ‘yes/no’ answer, the scale is deliberately designed to yield no such thing.

4. Residual liberty

4.1 The inability of the DoLS to conceive of liberty clearly also renders them incapable of engaging with the notion of residual liberty.111

4.2 It is sometimes suggested that although I might lose my liberty, whether by order of the court or because of my mental disorder, I do not lose so much of it that I cannot subsequently lose more.112

4.3 This implies an incremental process, yet the DoLS require that the specific point be ascertained at which an individual is deprived of liberty.

5. Purpose

5.1 It is sometimes said that the purpose for which an intervention is made is relevant to whether that intervention amounts to deprivation of liberty; and that no intervention will amount to deprivation of liberty that is carried out with benevolent intent.113

5.2 The ECtHR has, of course, refuted that argument.114

5.3 In any case, the argument flatly contradicts the decision in the Bournewood case.115 There, the ECtHR found that a man had indeed been deprived of liberty where he


113 Austin v The Commissioner of Police for the Metropolis (2009) UKHL 5; Cheshire West and Chester Council v P (2011) EWCA Civ 1257, per Munby LJ, at [102].

114 Austin and others v United Kingdom (2012) Application numbers 39692/09, 40713/09 and 41008/09, Decision of 15 March, paragraph 59. See also: David Hewitt, Purpose alone can no longer determine if there is a deprivation of liberty, Solicitors Journal 156/15, 17 April 2012.

115 HL v United Kingdom (2005) 40 EHRR 32.

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was confined to a hospital for three months and prevented from seeing his carers. The court accepted that the measures used upon the man had been in his best interests. If it had allowed that fact to preclude deprivation of liberty, the UK government would neither have lost the Bournewood case nor been forced to introduce the DoLS.

5.4 If purpose is relevant, the structure of the DoLS creates a paradox: the DoLS are relevant where an incapable person is deprived of liberty in his own best interests; yet, if strict observation of best interests will prevent there being deprivation of liberty, there will be no person to whom the DoLS apply.

5.5 And purpose creates a further paradox, beyond the DoLS: if, no matter how constraining they might be, measures taken in the best interests of a person will never amount to deprivation of liberty, what of people admitted to hospital under the Mental Health Act 1983? They might think they are being detained, but because lawful use of that Act demands a benevolent purpose, they would be wrong. Presumably, then, if they are not deprived of liberty, Article 5 of the ECHR does not apply and Mental Health Act patients do not need to have access to a Mental Health Tribunal.

6. Objection

6.1 It has also been said that where someone is subject to confinement, any objections he might have are relevant in deciding whether he is deprived of liberty. The Court of Appeal has said precisely that.\(^\text{116}\)

6.2 Previously, however, the Court of Appeal had suggested that the opposite was true.\(^\text{117}\)

6.3 This suggests that, as far as the DoLS are concerned, there is emerging a discrete conception of deprivation of liberty; one that owes little to the established authorities.\(^\text{118}\)

7. Normality

7.1 It has been said that in deciding whether someone is deprived of liberty:

(a) one must consider the “relative normality” of the situation; and

(b) in the case of an adult with disabilities, one must compare him/her not with “the able-bodied man or woman on the Clapham omnibus”, but with someone of the

\(^{116}\) P and Q v Surrey County Council and others (2011) EWCA Civ 190, per Wilson LJ, at [25].

\(^{117}\) Meering v Grahame-White Aviation Co Ltd (1920) 122 LT 44, 51, 53.

\(^{118}\) David Hewitt, Objection, purpose and normality: three ways in which the courts have inhibited safeguarding, The Journal of Adult Protection, 2012, Volume 14, Number 6, pages 280-286. See also: David Hewitt, A contradictory approach to deprivation of liberty, Solicitors Journal 156/26, 3 July 2012.

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same age as the disabled person, with the same capabilities and “affected by the same condition or suffering the same inherent mental and physical disabilities and limitations”.119

7.2 This is a subjective test, and it entails that mentally incapable people are afforded less in the way of liberty than the rest of us.120

7.3 This test also produces curious results, for example, that a man is not deprived of liberty, even though: every aspect of his life is supervised by a local authority and its staff; he is required to live at a care home and may not leave it unescorted; he has little privacy; he is sometimes placed in restraint; he is required to wear a one-piece ‘body-suit’; and he is often subjected to an intrusive ‘finger-sweep’ of his mouth.121 This is a decidedly subjective test.

7.4 In other areas of social welfare law, however – where, as here, it is necessary to assess the extent to which a person’s life diverges from the ‘normal’ – the test used is an objective one.122 That is so, for example, in Disability Living Allowance cases, where the comparator is “an ordinary person, who is not suffering from any disability”.123

7.5 If a comparator really must be used, therefore, it need not be a subjective one.

8 July 2013

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119 Cheshire West and Chester Council v P [2011] EWCA Civ 1257, per Munby LJ, at [102].

120 David Hewitt, Deprivation of liberty can never be normal, Solicitors Journal 156/220, 22 May 2012. See also: David Hewitt, Objection, purpose and normality: three ways in which the courts have inhibited safeguarding, The Journal of Adult Protection, 2012, Volume 14, Number 6, pages 280-286.

121 Cheshire West and Chester Council v P [2011] EWCA Civ 1257.

122 David Hewitt, Comparison contrast, Solicitors Journal 157/16, 23 April 2013.


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Overview and context-

1. To what extent has the Mental Capacity Act 2005 (MCA) achieved its aims?

The MCA is an innovative and positive piece of legislation which has achieved its aims in protecting some of the most vulnerable people in our society, by introducing lawful guidance on how to make decisions on behalf of people who lack capacity. It provides a statutory framework for professionals and lay people.

2. Which areas of the Act, if any, require amendment; and how?

What would be more helpful would be clearer definitions on decision makers and what decisions they can make; restrictions and proportionate response and how it is applied – this can lead to disparity due to lack of clarity on what these terms mean and how they should be interpreted and by whom. There is clearly a fine balance between giving guidance and not being too descriptive.

A real positive part of the MCA is the ability to look at cases individually and apply the act to the specific situation, this does not allow for generalisations, and in our experience, can if used creatively, empower professionals to really consider opportunities/options which might not have been tried in the past. The least restrictive option—this could be clearer. There has, in our experience, been a misunderstanding of this interpretation—people believe that the least restrictive option MUST be applied regardless not realising that the least restrictive might not be the best option to meet the individual needs.

3. At the core of the MCA are its principles and definitions of capacity and best interests. Are these appropriate?

The principles of the Act are clear, succinct and appropriate.

Implementation-

5. From our experience there is areas of great knowledge and areas of very little knowledge. This is apparent in professional groups; providers, organisations and the general public. Training and information giving in different organisations is given different priority. It appears to us changes arising from PCT to CCG has left a void in communication as its not as easy to acquire the relevant information, partnership working and training. Further information to families and the general public would be more helpful for sustainable to be possible. From our experience there has been a marked change in ensuring staff receive the appropriate training for their level of qualification and decision making. There has been an improvement in the recording of MCA and BI. There is still a way to go before we see a sustainable change in certain groups, it seems a slow process but there is a gradual improvement overall.

7. Since the Act has come into force, there does not appear to be a significant understanding of it amongst those who are directly affected by it and their non professional carers. For example, family members are frequently unaware that such an act exists and many believe that having a POA entitles them to be able to make decisions over all aspects of their lives.

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relative's situation, not just finances and property. A very small number of family members or friends appear to have Health and Welfare LPAs, and those who do, more often than not do not understand what this entitles them to do or prevents them from doing. Many feel that even if the person is able to make their own decisions, because they have an LPA, this means they can decide for them. Some carers do feel more reassured that they can act keep someone safe, for example, by making a medical or other appointment for them if the persons does not want one doing, or by locking a front door when the carer is in another part of the house to prevent them from leaving as it is in their best interests, and this does provide protection under section 5 for many situations. In order to provide more protection for the cared-for who lacks capacity, more education is needed for non professional carers, whether they hold LPAs or not. This would enable a better balance to be struck between protecting carers and the people they care for who lack capacity. The guidance around Best Interests Decisions has, however, allowed clearer consultation and involvement of the cared-for person and their carer, as, for example, it clearly needs to be noted in assessments how the cared-for individual's wishes and feelings have been taken into account, and what the views of carers are.

**Decision making:-**

13. Has the role of the IMCA succeeded in providing a voice for clients and an additional safeguard against abuse and exploitation for those who have no-one to speak on their behalf?

Yes we do believe that the IMCA has succeeded in providing a voice for clients.

14. Has the level of referrals to IMCAs met expectations? What are the reasons for the regional variations in the number of referrals?

We would like to see more referrals to IMCA in relation to safeguarding and change of accommodation. Regional variations could be due to the term 'unbefriended' and its interpretation by the IMCA and professionals in general. The professionals and the IMCA do not always hold the same view that someone is 'appropriate to consult' or unbefriended'.

15. Are IMCAs adequately resourced and skilled to assist in supported or substituted decision making for people lacking capacity?

It has been our experience, that on occasions, it appears that the IMCA, when representing the person has not taken into consideration the impact of the person's disability, diagnosis or lack of capacity. Clearer guidance to the IMCA on their specific role would be helpful. This could include more training on illness, ill health and its associated problems which may be helpful to them.

**Deprivation of Liberty Safeguards**

16. Are the safeguards in the Deprivation of Liberty Safeguards adequate?

This is quite a difficult question to answer. There being no clear definition of what constitutes a DOLS. Conflicting case law and court judgments has added to the confusion and lack of clarity. It is our experience that its implementation can be very protective for people who lack capacity; we have seen some very positive outcomes. As with the MCA there are large gaps in some individuals, professional, organisations and providers knowledge in order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
in its implementation which needs addressing. The issue of article 8 is complicated also, as this not only refers to the RP but their family member or relative as well. The cases which are required to go to court, in our experience take a great deal of time and often at considerable cost, which is compounded by reductions in LA budgets. If an alternative, quicker and less costly arena were to be identified this could be more effective but it would have to ensure that the right of the RP was not compromised. Conditions on the Authorisation are placed on the MA and not the funding authority. If conditions were able to be placed on the funding authority it is likely more changes could occur to reduce the number of restrictions or deprivation quicker and more effectively. Managing Authorities have little power to make changes that result in more resources or more cost to themselves.

17. Are the processes for authorisation, review and challenge of DoLS sufficiently clear, accessible and timely?

It is our opinion that the process of authorisation, review and challenge is clear on most occasions but it is questionable that if families and carers have insufficient knowledge and/or experience of MCA/DOLS they may not utilise these issues.

It is often the case in our organisation that the SB will call a review depending on the individual situation and if it is felt the person’s situation needs to be monitored or changes need to be made to their current situation. A review is rarely called by the RP or the RPR or the managing Authority.

Other legislation-

24- How well is the relationship with the mental health system and legislation understood in practice?

There continues to be difficulties with the interface of the MHA and MCA. This would appear to stem from lack of understanding, knowledge of the legislation. Interpretation and guidance from case law; COP; Jones Manual appears to make it more blurred. I have been personally involved in cases when intense discussion has taken place to ensure that the patient in a psychiatric hospital is detained/deprived under the appropriate legislation. If a patient is not detained/deprived under either of the Acts when it is required, it does in my opinion leave the reason for the DOLS and the Bournewood gap meaningless, leaving the person unprotected in law.

The information above is gathered form the views and experiences of a small group of BIA’s employed by Norfolk County Council and does not necessarily reflect the views of the Council.

1 September 2013
Hft – Written evidence

1. Hft’s Family Carer Support Service welcomes this opportunity to make a response to the Lords Select Committee review of the Mental Capacity Act.

2. Hft’s Family Carer Support Service (FCSS) provides information and support to family carers of people with a learning disability anywhere in England.

3. We do this by responding to individuals who request help by telephone, email and letters; through participative workshop courses so groups of relatives acquire skills and knowledge they need to understand and engage effectively in processes affecting their relative and themselves; the production of resources specifically tailored to the support roles family carers play throughout phases and aspects of their relative’s life; and by working in partnership with others to help raise the profile of family carers, their needs and contributions, in research, health and social care, as well as mainstream, initiatives.

4. Our response to the Lords Select Committee on the Mental Capacity Act 2005 is based on experience gained delivering the above services to family carers of relatives with a learning disability, as well as though exchanges with colleagues in the National Family Carer Network (specifically Paul Swift, an NFCN Associate) and in particular our

   a) Experience of developing “Using the Mental Capacity Act: a resource for family and friends of people with learning disabilities” and running training sessions on the Act for family carers and staff across the country;

   b) Providing support to individuals who contact us about situations they find themselves in;

   c) Participating on the Confidential Inquiry on Premature Deaths of People with Learning Disability (CIPOLD) on Overview Panels as well as the Advisory Group;

   d) Communicating with Skills for Care and other professionally focussed agencies.

5. Has the Act made a difference to family carers - if so how?

   a) Yes. It sets out expectations about how everyone, including family carers, should assess capacity and make best interests decisions.

   b) It formalises the role of family carers when someone lacks capacity, recognising the important contribution they can make as substitute decision-makers and as consultees. The Code of Practice places a duty upon health and social care staff to involve family carers at all stages.

   c) The Act and the Code of Practice should give families confidence that learning disabled relatives will have their capacity properly assessed and that the people in their lives will be acting and making decisions in their best interests.
d) The Act provides ways for family carers to hold health and social care staff (and others) to account for their actions, by challenging assessments of capacity and best interest decisions, DoLS applications and the actions of substitute decision-makers.

e) The Court of Protection has shown itself to place a high value upon the maintenance of family relationships in the application of the Act.

6. But many family carers are not made aware of the MCA and how it applies to them.

7. We have had an extremely positive response to our offers to run workshops for family carers about the Mental Capacity Act, based on the resource “Using the Mental Capacity Act: a resource for family and friends of people with learning disabilities”. In the past 12 months we have spoken to over 400 family carers at events around the country, and answered innumerable questions.

8. When families understand the Act and the processes described in the Code of Practice they are able to understand the reasons for there being a change of emphasis in their role as their relative moves into adulthood. This is relevant at and beyond the “transition phase”. Parents (or other family members) need to know that, by law, they are no longer decision-maker by default as is often the case when your son/daughter, brother/sister is a child. It is helpful that families understand staff need to do all they can to ascertain the views of the individual and that relatives have crucial roles to play in, for example,

a) checking no wrong assumptions have been made about capacity,

b) there is clarity about the actual decision to be made,

c) information has been appropriately offered to the individual,

d) implications of decisions have been explained as fully as possible,

e) the significance of NOT making a decision is understood.

9. In addition, if their relative has been assessed as lacking capacity, family carers who understand the Act know that their relative should still be involved as much as possible in choices; guidance about Best Interests Meetings is more likely to be followed; substitute decision-making is understood better; DNARs are more likely to be issued correctly. The Act can work better when relatives know what to expect of staff and what they can do to achieve their family member’s rights!

10. Lacking information about the MCA and how it works, has led family carers to come to us traumatised, in anxiety or confused when, for example:

a) A relative has died in circumstances that gave no consideration to the culture or beliefs they held precious – had the family known that her Best Interests should have been considered and that they were entitled to give their views of what her choices would have been they would have cited the Act and been much more likely to insist it was followed with the result that their relative would have had better care and a better death. They would not
have been so haunted by feeling they had let her down, nor so angry about statutory services they still needed to work with concerning another family member;

b) Parents felt suspicious they were not being asked to accompany their son to make a statement about a safeguarding incident at the police station – the situation was serious, wasn’t there a Capacity Act that said they should be more involved? We were able to check their, and other people’s, views of their son’s capacity, what information they as parents understood he had been given about making a statement and its consequences and whether they had concerns about how he was being supported. Since all of this was satisfactory we moved on from the MCA to describe the risk of contaminating evidence if their son began to discuss what had happened to him before giving a statement to the police with the result that the parents felt reassured and co-operative towards the residential college staff rather than threatened and challenging. Had they understood the Act much discomfort would have been avoided.

11. If families associated with individuals living at Winterbourne View or Staffordshire Hospital had known about the MCA they may well have alerted safeguarding teams directly; they did not understand the legitimate roles they could play under the Act.

12. Both fieldwork prior to developing “Using the Mental Capacity Act” resource for family and friends and while giving presentations about it since, have demonstrated that:

a) For families of young people it can be a shock to suddenly be confronted with a new way of making decisions for someone who lacks capacity when they reach adulthood (and many are unclear that most of the MCA applies from 16);

b) Some family carers feel that the MCA is used by professional to ‘get their own way’ and do not feel empowered to challenge actions and decisions made by professionals under the MCA;

c) Procedures for substitute decision-making (especially deputyship) are expensive and appear involved;

d) The Court of Protection seems daunting.

13. We believe information about the Act, and where to get support to ensure it is applied, should be given to parents of young people with SEN routinely as part of the transition process when their son/daughter moves into adulthood. This is an opportune time to explain how the Act works from 16 and upwards to ALL parents of young people for whom the Act is relevant – if it is missed the knowledge may only reach those who stumble upon it, are advised to seek it out or meet helpful, informed professionals.

14. What are the good things about the Act - can you give examples?

a) The presumption of capacity and the decision-specific principle that underpins its application offers powerful protection to people who lack capacity.

b) The presumption (linked to the above) that decisions under MCA will be evidence based. There are assumptions that there should be a care plan and care pathway and
thereby assumptions that efforts will have been made prior to any formal procedures to engage and support the individual to have a good quality of life.

c) The clear procedures for assessing capacity and making best interests decisions for someone who lacks capacity. The Code of Practice is a long document, but it is very well written and offers lots of good examples of how the Act should work in practice.

d) The inclusion of criminal offences about mistreatment and neglect. This gave a potential way of dealing with the perpetrators of abuse at Winterborne View.

e) The possibility of independent advocacy (eg around decisions about health care, well-being, property etc).

15. What needs to be improved - why?

a) Because the MCA is often used in a crisis, it is important for carers to ensure that as far as possible their relative does have a care plan, a care pathway which sets out what he/she and the family want and what steps the relevant professionals have taken to achieve the goals set out in any plan. Good practice would be something like the Passport for health care and decision making (St Richards Hospital) and the Dementia Passport (Surrey NHS and local authority). Many of the issues around learning disability are very similar to those around dementia and there could be some shared learning.

b) More support and information for family carers to ensure that they understand how the MCA applies to them – this is especially important for family carers of young adults.

c) DoLS procedures need to be simplified and clarified.

16. Awareness of the MCA and how it works.

a) The duty set out in the Care Bill for local authorities to provide or facilitate the provision of information and advice services could, hopefully, raise awareness of MCA. However “awareness of the MCA” is unlikely to be an adequate knowledge base if information and advice services are to be of practical value to carers. Access to support from someone with a real working knowledge of the Act will be crucial in supporting casework. Service Level Agreements could usefully include monitoring the difficulties encountered locally to increase the chance of improving its use over time.

b) Many families are totally unaware that the enduring power of attorney has been replaced and do not understand the role of the deputy (or deputies if there are dual issues, eg finance and health decisions to be made. CQC, in its report on the use of the MCA 2011/12 notes that 1 in 5 patients did not know of their right to have an independent mental health advocate and were generally unfamiliar with the MCA).

c) With regard to the above, CQC also found that although PCTs (and now, presumably CCGs) have had a legal duty to provide independent mental health advocates since 2009 to all qualifying detained patients and patients subject to a community treatment order or guardianship, this was not always the case. Regular access to independent mental health advocates was a problem in over a quarter of the wards visited. This has particular implications for people with learning disabilities and their families (or people with dementia, in order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.)
when there is cognitive impairment) because there may be a range of additional issues to be considered in helping them make the best decisions about treatment, discharge etc.

d) CQC (cited above) found that carers generally did not feel that they received adequate information. They reported that police officers, approved mental health officers and clinical staff and others sometimes assumed that they had a level of knowledge about the Act and local services that they did not have.

e) The promotion of simple, cost-effective ways to resolve disputes before they escalate to the Court of Protection.

f) Ensuring that health and social care professionals understand their duties and obligations to involve family carers.

17. Professionals lacking information about the MCA and how it works has led family carers to come to us traumatised, in anxiety or confused because, for example

a) They had begun to seek support from the Solicitor General as litigation friend because they did not feel they were being listened to when expressing their view that removing all their daughter’s teeth at once was not the right thing for her – through giving the registered care home where the daughter lived more information about the MCA, particularly the need to seek further views on the least restrictive option and to have full Best Interests Meetings where all views were heard and considered, a second medical opinion was sought. As a consequence only some of the teeth were removed under surgery and a good cleaning protocol was instituted to maintain others as long as possible.

b) A sister feeling side-stepped and taken out of “the review meeting loop” by a supported living provider after missing a meeting because of the way her brother was asked who he would like to receive copies of a meeting’s minutes - “Shall we give them just to the people who were at the meeting?” He had answered “Yes”. No-one had explained this would mean his closest relative, who usually attended all reviews, would not know what was talked about, what actions people had committed to take, nor when the next review would be held. It appeared no-one noted this was a change of routine or checked its consequences were understood and chosen. When the sibling asked the provider how her brother had been supported with the decision not to include her in minutes circulation they admitted there had been no support offered. After checking with the man again, the service sent the minutes to his sister.

c) The “Using the MCA” resource films includes an example of the inappropriate use of IMCAs where there were family carers to consult.

Professional practice

18. It is important that professionals understand that family carers are usually best placed to i) provide information about a learning disabled relatives capacity, needs, wishes, preferences, previously expressed opinions etc, ii) ensure that a best interests decision is turned into action, and iii) be the ‘eyes and ears’ to check that a relative’s best interests are being served.
The two year DH funded CIPOLD study investigated every death of a person (aged 4 and over) with learning disability across 5 Primary Care Trusts. Repeatedly at Overview Panels we noted that practitioners associated with healthcare had not followed the MCA although all had presumably been required to sign they knew their responsibilities under the Act:

a) capacity was sometimes assumed/deemed lacking without assessment,

b) decisions were taken without involving individuals - or their relatives if the individual had been assessed as lacking capacity to take decisions about a treatment – eg staff sometimes decided people would not like, or cope with, treatment with fatal results,

c) DNARs were used without procedures being followed,

d) there were disagreements about what constituted a serious medical condition requiring a Best Interests Meeting

e) doctors were still asking relatives to sign “consent forms” and seeming to think that the MCA was only about agreement to treatment rather than a whole approach to involving people who may lack capacity in decisions affecting them and, if assessed as lacking capacity for a particular decision, those who know them well or IMCAs.

The government’s response to a CIPOLD recommendation about the need for a specialist helpline to support people with the MCA was that this support is available within each authority already. This is not our experience, nor that of the medical staff who saw this as an effective way to encourage learning and resolution of difficulties without resorting to the Court of Protection.

Family carers would also welcome a national helpline which gave expert advice quickly to avoid the complexity, expense and time taken to apply to the Office of the Public Guardian for help.

When training is developed for professionals it should include the role of close relatives and friends and examine how best to include them.

The new Training Awareness in the Mental Capacity Act 2005 qualification developed by Skills for Care (SfC) (http://www.skillsforcare.org.uk/qualifications_and_training/adultsocialcarequalifications/AwarenessoftheMentalCapacityAct2005.aspx ) has a disturbing lack of reference to family carers. This means that staff taking this course might pass it without any sense of the need to involve carers in helping to assess capacity, discuss ideas about good communication with them, welcome their support to involve people in decisions affecting them, help explain Best Interests Meetings to them and run these in effective inclusive ways, encourage them to challenge if they believe staff are not operating within the law etc.

When we contacted someone from the SfC’s relevant Standards, Learning and Qualifications team about this they did not seem to understand our disappointment that no mention was made of relatives, friends, family carers within the unit about MCA awareness.

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We were told the person who wrote the unit was an expert who said in response to our message that the unit was only about the law and he apparently expected practice support resources would raise issues related to non-professionals. The author of the unit appeared blind to the presence of carers within the law (despite what sections 4 (&) and others say) or guidance and SFC seemed to disregard the fact that family carers are the biggest workforce supporting frail people/those with disabilities and a key element of paid staff's working “environment”.

26. If you could make a key change to the legislation or the way it is implemented, what would it be?

27. We would be cautious about suggesting changes to a piece of legislation that is still relatively new, but prefer further focus on getting implementation right – ensuring that everyone involved understands the law and how it applies to them through active monitoring.

28. One area of concern is the local arrangements that are in place for monitoring implementation: have the original implementation mechanisms survived the latest local authority cutbacks, are the right people (including family carer representatives) involved, do CQC and others include the MCA in their remit?

29. We would like the CQC, in its annual report on MCA, to ensure that the examples (and the inspection visits) include learning disability. Post Winterbourne View, the issues are even more important.

30. In addition to CQC’s regular scrutiny, it would be good if Healthwatch could also monitor what is happening with regard to MCA (ie the experiences of particular groups of patients who are subject to MCA procedures and of course the views of their carers) because of it is national and local and covers health and social care.

31. IMCAs

32. During oral evidence sessions we noted a question that related to the possible extension of circumstances when IMCAs could be made available.

33. Any consultation on this needs to make clear whether this consideration is of IMCA support being made available for the individual assessed to lack capacity and/or their family/friends.

34. Some oral submissions to the committee seemed to assume they were being asked about likely views of extending IMCA support to enable family carers to get their views heard. If processes are followed according to current advice this should not be necessary, family members/friends should be encouraged and supported to give views, they should be listened to and considered alongside others’ for the decision maker to reach a Best Interests Decision.

35. If instead, the question is about broadening access to IMCAs to people who are assessed to lack capacity for the decision in question, although they have relatives/friends who could represent their views, we feel there would be mixed views.
36. In our experience this could be welcomed by some relatives who feel they are not able to give a useful view on a particular decision, but believe that a trained person - with experience of communicating with individuals with learning disability who they do not otherwise know - would be able to advocate well for their family member or friend. (We recall a mother saying “I know what I would like for him as his Mum but I don’t necessarily know just what he would want”.)

37. However, extending access to IMCAs could be seen with suspicion and as a threat. It will be important to clarify when such IMCA input might be offered/provided. Will this be when family member/s ask for it or could it be when professionals want back-up for their own views against family input they believe is not in the individual’s best interests? The latter seems dangerous.

38. Summary and recommendations:

39. The MCA has improved decision making procedures, provided a good framework for dealing with differences of opinion and working together for the benefit of people who may lack capacity. We would be cautious about suggesting changes to a piece of legislation that is still relatively new, but prefer further focus on getting implementation right – ensuring that everyone involved understands the law and how it applies to them through active monitoring.

40. More carers should be provided with practical information related to their situation about the Mental Capacity Act. This should be offered on a statutory basis to parents of young people during the transition of their son/daughter into adulthood. (There should not be reliance on national voluntary helplines or casework support being available – Mencap’s helpline and casework system has been slashed this year and other major voluntary sector services may also disappear.)

41. Service Level Agreements for local information and advice services should ensure carers get access to support from people with specialist knowledge of the way the MCA works, and provide information to the local authority about the difficulties encountered so that learning and preventative work take place in order to improve knowledge and practice.

42. Professional training and inspection needs to be ongoing, more thorough, practical and cover the roles of close family and friends and how best to implement the Act with their input.

43. There should be a national-helpline providing specialist assistance in complicated situations, an alternative to going to the Office of the Public Guardian or Court of Protection that avoids the costs and complexities, which monitors difficulties encountered and feeds back into training needs and inspection requirements.

44. Any changes considered should be widely consulted on and if there are to be any modifications they will need to be implemented through a full programme of awareness-raising in voluntary, statutory and commercial arenas.

2 September 2013

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.

Submission to be found under Victoria Butler-Cole.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Housing and Social Care Services, London Borough of Camden – Written evidence

Overview and context

To what extent has the Mental Capacity Act 2005 (MCA) achieved its aims?

The MCA has achieved the aim of providing a clear legal framework around decision making for those who lack capacity and if followed ensures that people are supported to make decisions and for those made on their behalf to be best suited to their best interests. However six years after enactment there are still issues with following the Act.

1. Whilst most professional groups and settings are aware of the Act, the level of understanding across all groups varies considerably. There are many health and social care professionals who do not understand the concepts of capacity and best interests.

2. Many professionals lack confidence in using the Act; for example, there is frequently a reluctance to assess capacity, even when the professional is clearly the most appropriate person to undertake this role. The latest move by the Court of Protection to amend the ‘COP3’ mental capacity assessment form is welcomed. This will make it clearer that the assessment is not limited to psychiatrists and psychologists, and other professionals such as social workers and nurses can potentially complete the form, if they have the expertise.

3. Its existence is not widely known or understood by those outside of the health and care professions. Therefore for persons affected by the Act or those who are caring for the person, this can be seen as a process done to them, rather than as a tool to enablement and protection.

3. There is one key principle from section 1 of the Act which needs further focus: principle 2: “A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success”. This is crucial in maximising the ability of people to make their own decisions, even when they have significant cognitive impairment or disability of mind. However, there is concern that the professional focus is more frequently on the assessment of capacity and best interests decision making, which can be seen as more tangible and boundaried activities.

Which areas of the Act, if any, require amendment; and how?

Schedule A1 of the Act, the Deprivation of Liberty Safeguards (DoLS) has always caused huge difficulty in its interpretation and use. It remains poorly understood by many of those who need to particularly hospital and care home staff. Even amongst those professionals who have studied them in detail, including solicitors, social workers and medical professionals, there continues to be considerable variation in understanding and interpretation. This is reflected in the considerable variation in DoLS activity across England. This relates both to referrals for standard authorisations by hospitals and care homes, and to the proportions of assessments which lead to an authorisation by the Supervisory Body. These variations emerged at the time of enactment, and in our view do not seem to have reduced in the subsequent four years. This recognizes that statistical reporting is annual so our view may be outdated.

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There is some concern that the appeals process for DoLS does not sufficiently address the need for a speedy review of a person’s detention by a court, as required by the European Convention of Human Rights Article 5(4). The legislation does not mention the word ‘appeal’, instead providing two routes for a person’s detention to be reviewed, only one of which involves a court. The non-judicial route is when the ‘relevant person’ requests a review of their detention (Schedule A1, para 102). Although the legislation requires the Supervisory Body to arrange for a review in this circumstance, para 110 allows the Supervisory Body to take no further action if it considers none of the qualifying requirements appear to be reviewable. Thus the only review which the Supervisory Body is required to undertake is a paper exercise, and there is no binding requirement to fully review the authorisation.

The judicial ‘appeals’ process is only via an application to the Court of Protection. This is a cumbersome and lengthy process. Since the expansion of the remit of the Court of Protection following the enactment of the Mental Capacity Act in 2007, the number of applications has risen consistently, and the Court has found it increasingly difficult to respond speedily to applications. It is suggested that the delays in hearing applications which are challenging a standard authorisation may be challengeable under the ECHR Article 5(4) as mentioned above.

The Mental Health Act has a much simpler and speedier method of independent review of detention; the mental health tribunal. Since 2008 there has been a First Tier Tribunal and an Upper Tribunal for appeals against the decision of the First Tier Tribunal. This process should be further explored to relieve the pressure on the Court of Protection and allow a more efficient and speedy method of appeal for people subject to standard authorisations.

The Act omits any explicit power to convey or return a person to a place or residence, even if there is a DoLS authorisation in place. Nor is there a speedy mechanism that enables professionals to make an application to the courts for this purpose. This therefore leaves a gap, and particularly where there are issues which are complex and challenging. At present the only recourse is to make an application to the courts which can be administratively cumbersome, as well as costly, through a system that appears to have little capacity to provide an immediate response to these types of situations, as mentioned above. In addition, Professionals do not feel confident that there is sufficient protection from the Act or guidance within the relevant codes that can provide support with these situations. It would be helpful if some legislative authority was immediately available; and/or whether the DoLS legislation could include the power to convey and return as does Guardianship.

The eligibility requirement, set out in Schedule 1A continues to cause confusion and conflict amongst professionals and highlights a difference in thresholds between the application of the Mental Health Act and DoLS. The wording of the Act makes it difficult to interpret, where DoLS applies and where it does not. Where a person has failed the eligibility assessment, there is often reluctance to formalise their detention under the Mental Health Act.

There is a view expressed by some mental health professionals, that not placing a person under the Mental Health Act is actually a less restrictive approach. Whilst we have seen an increase in our referral rate for authorisations from hospitals, there are still very few applications in relation to Mental health Wards. It is likely that there are a number of people in these types of settings who lack capacity, but are not subject to any regime, and whose in order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
rights are not being protected in any way. It would be simpler if the DoLS legislation did not apply to these types of settings and that the use of the Mental Health Act was promoted for all those who lack capacity to consent to their admission and treatment, rather than relying on the additional concepts of whether they would or would not object if they had capacity to do so.

At the core of the MCA are its principles and definitions of capacity and best interests. Are these appropriate?

As mentioned above, the principle of assisting people to make decisions and not determining that they are unable to make a decision until all practicable steps have been taken is at times given less focus than the capacity and best interests principles and definitions.

In order to maximise the ability of people to keep control of their lives and make their own decisions, this principle needs to be given equal focus.

**Implementation**

To what extent have the five principles of the MCA been implemented in frontline practice? What evidence is available to assess this? Is there a satisfactory balance between enablement and protection?

Since the implementation of the Act, progress has been made with professionals’ and organisations’ understanding and implementation of the Act, into day to day practice, and we have seen examples of good practice and compliance with the code. For example imaginative methods of providing information to the relevant person concerned, such as using variety of visual aids; or postponing assessments until necessary audio equipment is available to assist with communication. However with some settings and/or professional groups this progress has been slow.

In some settings, such as large health settings, it does not appear that the culture of decision making has changed significantly and more work is needed in order to achieve this cultural shift. Most staff within these settings have received limited initial training, however there appears to be limited opportunity to undertake refresher training or have awareness of case law updates. Many organisations provide mandatory training in topics such as adult protection, but it is rare that mental capacity training is included in the mandatory schedule. Given the very large proportion of adults known to health and social care agencies who lack capacity to make some decisions, or who will have difficulties related to their cognition, a greater requirement for regular training would help to address this issue.

We find that whilst most health and social care professionals are knowledgeable about the principles and definitions, the main difficulty is implementing these into day to day practice, given the variety of types of decisions that are required.

The code of practice in its current form, whilst extremely detailed can present as unwieldy and does not always provide sufficient guidance to professionals for the variety of real life complex decisions that are required.

Is the Act widely known and understood by professionals required to implement it? How does this differ across different sectors, such as health, social care, banking and others?

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We find that the knowledge and understanding of the Act varies across the professionals and types of settings.

We find that Social Workers have a better understanding of the Act than most other health and social care professionals.

The nature of the decisions that Social Workers are involved in, demands a higher level of formal recording, normally in pre-constructed formats that follow the requirements and principles of the Act.

The decisions that require their involvement are generally long term requiring significant planning and consideration.

The accompanying general social care processes and structures are also likely to act as ‘check and balance’ mechanisms for ensuring that the Act is being followed and used appropriately.

In health settings or amongst health professionals, whilst known, the level of understanding of the requirements and their implementation, is less understood. The Mental Capacity Act in our view can be seen as legislation specifically for social care professionals.

In large health organisations that have developed policies and have specific organisational leads that are pro-active in addressing MCA issues, the implementation of the Act is more robust.

The transitionary nature and turnover of staff and management within health and care settings can provide obstacles with developing consistent organisational understanding of the Act. Whilst training maybe given at a point within a year, the frequency of staff changes can result in limited coverage for that cohort.

Is the Act widely known and understood by those who are directly affected by it and by their non-professional carers? To what extent does the Act provide protection and reassurance for informal carers? Has the right balance between struck between protection of the carer and protection of the individual lacking capacity?

As stated above, whilst most non-professionals are aware of the concept of capacity there appears to be little awareness of the actual legislation and its purpose.

Has the Act ushered in the expected, or any, change in the culture of care?
No response is offered as the views in this response are representative of a small group who would be unable to provide an evidenced based view on this.

Is there any evidence that the provisions of the MCA affect some groups disproportionately? If so, what data exists to compare representation across different socio-economic groups, Black and Minority Ethnic groups, and gender?

From Data Collected since April 2011, 86% of people who underwent an assessment of capacity were classified as whitewith 88% assessed as lacking capacity. In comparison with ONS statistics this is a higher proportion than the area demographic of this particular group, 66%.

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At present there is no evidence to suggest that Black and Minority Ethnic Groups have been disproportionately affected by the Act. The percentage of those who underwent an Assessment of Capacity and those who were assessed as lacking capacity is less than the Area Demographic profile. This may be due to the large proportion of older adults who are affected by dementia and loss of cognitive function. This age group is likely to contain a higher proportion of people with White British and Irish background than the population as a whole. Similar results apply to Gender.

**Decision-making**

Are those directly affected by the Act being enabled and supported to make decisions for themselves to a greater or lesser extent than they would have been in the past? Does the means by which the decision is made – ‘general authority’, Lasting Power of Attorney, deputyship, Court of Protection – affect the quality of decision making?

It is difficult to draw a comparison between whether people are better enabled or supported than previously. What the Act has done is to ensure that decisions are evidence-based and has enabled professionals to be more aware of the decision making process.

Whilst most professionals are fully aware of the Mental Capacity Assessment process, the Best Interest decision-making process is still an area that requires further development. It would appear that some professionals are still motivated by the ‘protection imperative’. This concern has been raised in a number of reported Court of Protection judgments. The Court has also commented on the risk of professionals determining capacity on the basis of the perceived wisdom of the decision being made, rather than the quality of the relevant person’s decision-making ability.

What evidence is there that advance decisions to refuse treatment are being made and followed?
No response (please see 8)

Has the MCA fostered appropriate involvement of carers and families in decision-making?
No response (please see 8)

Has the role of the Independent Mental Capacity Advocate (IMCA) succeeded in providing a voice for clients and an additional safeguard against abuse and exploitation for those who have no-one to speak on their behalf?

The development of the IMCA service is an important additional voice for people who are at risk of being disenfranchised from the decision-making process, and who have the most difficulty in expressing their own wishes and feelings.

There is a risk, however, that the IMCA promotes a view which is more in accordance with the care, at the expense of the expressed wishes of the relevant person, particularly when the two are in conflict.

Any guidance issued for the IMCA role needs to ensure that there is a focus on the individual’s viewpoint.

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Local statistics show that there are very few challenges to decisions, both in terms of the main Act and Schedule A1, which would appear to support national figures.

Has the level of referrals to IMCAs met expectations? What are the reasons for the regional variations in the number of referrals?

Locally, the number of IMCA instructions has increased year on year since the enactment of the legislation. Our findings are in line with national figures, that the use of IMCAs is greater for accommodation decisions, and less instructions are made for care reviews and safeguarding decisions. The availability of an IMCA in safeguarding cases is an important additional support for the relevant person, and any development of adult safeguarding guidance should explicitly reference the IMCA role, and the duty of the local authority to consider instructing an IMCA if it would be of benefit to the person.

We are unable to comment on regional variations.

Are IMCAs adequately resourced and skilled to assist in supported or substituted decision making for people lacking capacity?

Apart from guidance provided from the Social Care Institute of Excellence (SCIE), there do not appear to be any national standards or regulatory body that ensures that consistent professional standards are being applied.

Currently the role of monitoring of the IMCA role falls locally to commissioning bodies within local authorities and to individual IMCA providers.

We would like to see national standards set for the IMCA role which are transparent and allow a pathway of recourse to address any issues arising.

We would also like to see the IMCA role to be regulated by a central body much in the same way as other professional groups within Adult Social Care, either through a separate body or incorporated into an existing organisation.

**Deprivation of Liberty Safeguards**

Are the safeguards in the Deprivation of Liberty Safeguards (DoLS) adequate?

It is difficult to state whether the DoLS is adequate. Despite 4 years of implementation The Deprivation of Liberty Safeguards still appears to be misunderstood by significant numbers of social care professionals and others involved in a person’s care. Whilst it is essential that some sort of process exists that deals with these situations, the process and language is complex and appears to alienate all those who are affected, professionals and individuals alike. In addition, the lack of specific definition of Deprivation of Liberty often confuses professionals and they therefore are unaware when the threshold for Deprivation of Liberty has been reached.

The code of practice and legislation is worded in a way that managing authorities make the sole decision to deprive someone of their liberty; however the reality of the situation with regards to Care Homes is that they are often implementing a care plan devised by an

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external professional, such as a social worker. The code of practice makes little reference to the role of these Commissioners of Care with regards to this.

Managing Authorities often do not see themselves in the business of depriving someone of their liberty and find it difficult to accept that this is what they might be doing when providing care for an individual.

On the other hand, Social Workers will often view the DoLS process as something separate from the work they are doing with a person and often do not fully understand that it is their care plan that is resulting in a Deprivation of Liberty for that person and their on-going role when an authorisation is granted.

Are the processes for authorisation, review and challenge of DoLS sufficiently clear, accessible and timely?

Managing Authorities, both hospitals and care homes continue to be confused by the process. Managing Authorities have difficulty understanding the difference between the types of applications and the competing timescales. Nor do they understand the terminology of the DoLS process. There is often a need to coach managing authorities when the point of enquiring about making an application, that they had heard of DoLS but were unaware of the need for a formal application.

The burdensome nature of the forms could potentially discourage managing authorities from making applications.

The application process requires substantial information to be provided. The application forms are lengthy running to 18-20 pages.

Where an urgent authorisation is granted and a standard authorisation is requested, there is a significant amount of duplicated information required by the two standard forms.

It is view that often a significant amount of information is missing from the forms when submitted and in many cases the service has to return them to the managing authority for corrections.

It can take a significant amount of time and resources to extract these applications from the managing authority. Given the length of these forms and the amount of detail required, it can take several days from point of notification, for a managing authority to complete these and for them to be received by the DoLS Service in the local authority.

This risks compromising the already tight statutory timescales in which the assessment is required, particularly in relation to urgent authorisations.

In our view, managing authorities misunderstand the purpose of a Review (Schedule A1, Part 8) and when to request one. They often require prompting to request a review and require substantial support to understand why they need to do this. Nor do they fully understand the need to comply with conditions or the impact of non-compliance.

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The competing timescales for applications both in terms of length and timeframes results in considerable confusion, not just for managing authorities, but also for assessors and Supervisory bodies.

Most managing authorities and unpaid representatives do not fully understand the role of the representative. In our experience, managing authorities do not understand that they have a role in monitoring representatives and it is often not brought to the supervisory body’s attention that there are difficulties until the authorisation is drawing to an end.

Representatives often do not understand their role with regards to monitoring of the authorisation. Very few understand the concept of deprivation of liberty and the requirement to act in the relevant person’s best interests with regards to challenging the authorisation.

Whilst administratively cumbersome, DoLS has been able ensure that the rights and freedoms of individuals are protected. Simply to add the DoLS onto elements within the Mental Health Act would not in itself be sufficient. The current assessment process within the Safeguards provides an opportunity for a thorough independent, objective examination of a particular layer of complex situations. Often the issues that had led to a request for authorisation have been on-going for several months or years. The assessment, particularly the best interest assessment, provides the opportunity for a complete and holistic examination of the circumstances of that individual. Normal community care assessments and even Mental Health Act Assessments do not prompt the level of investigation that is required by the DoLS assessment process. The DoLS process can highlight whether the initial decision making processes have been fully considered and through recommendations can lead to a resolution of issues that have been on-going for a substantial amount of time. It also provides a mechanism for on-going monitoring of a person’s situation if cases where authorisations have been granted.

In one case we found that a person with complex mental health conditions had been cared for in a long stay mental health unit for over 19 years. When this unit closed, the person was transferred to a traditional mental health unit, along with the same staff. However at the time there was no assessment of whether this person could be moved to a less restrictive environment within the community as staff had never considered this option. The DoLS process has been able to highlight that these options need to be fully considered and examined and now these avenues are being actively explored.

The Safeguards would be adequate if the processes were made simpler and clearer; with clearer definitions of a Deprivation of Liberty; and enforceable sanctions against managing authorities who do not comply with the requirements of the Act. If the process is changed, it is essential that any replacement procedure ensures that the Best Interest Assessment remains an essential part of that procedure.

The Court of Protection and the Office of the Public Guardian

Are the Court of Protection and the Office of the Public Guardian sufficiently understood and accessible to all? Are they operating effectively and successfully?

Unlike the Children and Family Services or Mental health, where making legal applications form part of the daily practice, social care professionals are not generally familiar with the

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Court of Protection processes. Given the nature and variety of decisions that are dealt within Adult Social Care Services, the threshold for when a case requires the attention of the courts is unclear and the process for applications is administratively complicated through the number and variety of different forms; duplicated information; and timescales.

There is lack of specific guidance to supervisory bodies in respect of section 21a applications to the Court of Protection where the only person who is objecting to the arrangements is the relevant person. The current Act and Code places the responsibility for making applications under S21a onto the relevant person or their representative, however in most cases neither understand the mechanisms for doing so. For those who are significantly cognitively impaired, who continue to object to their detention, but do not have the ability to understand how to appeal or how to initiate an appeal, this leaves a significant gap as to whose responsibility it is to initiate any application.

What has been the impact of the introduction of Lasting Powers of Attorney (LPA), especially with regard to decision making on matters of personal care and welfare?

No response (please see 8)

What concerns, if any, are there regarding the costs associated with registering an LPA, or with making an application to the Court of Protection?

From feedback from social work professionals, family members often wished to be the persons to manage their relative's affairs however are often put off from making applications to the court of protection due to the costs involved as well as the administrative process. Where they may initially agree to make applications, once aware of the costs and the process they frequently return to the local authority to make the applications, particularly in relation to finances or tenancies.

Is legal aid available and sufficient? What impact will the recent and proposed reforms to legal aid have?

No response (please see 8)

**Regulation**

Is the role of the Care Quality Commission in inspecting on the MCA standards adequate and appropriate? Is there a case for additional powers?

It would be helpful if CQC were provided with additional powers that could specifically address issues where managing authorities appear not to be complying with a DoLs authorisation. At present there are no significant sanctions or reporting mechanisms for managing authorities who do not comply.

Should other regulatory bodies, such as health and social care professional regulators, be acting in this area?

No response (please see 8)

**Other legislation**

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
How well is the relationship with the mental health system and legislation understood in practice?

The relationship between the Mental Health Act and the Mental Capacity Act is complex and even those professionals who consider themselves to be well versed in both pieces of legislation struggle to understand the interface issues. This is reflected in a number of judgments of the Court of Protection and, more recently the Upper Tier Tribunal for the Mental Health Act.

Devolved administrations and the international context

Does the implementation of the Mental Capacity Act differ significantly in Wales?
No response (please see 8)

What lessons, if any, can be learnt from the approaches taken to mental capacity legislation in Scotland and Northern Ireland, or in other jurisdictions?

No response (please see 8)

Is the MCA compliant with the United Nations Convention on the Rights of Persons with Disability (CRPD)? Are there lessons that can be learnt from the CRPD for the successful implementation of the MCA?

No response (please see 8)

2 September 2013
Introduction

1. The evidence presented below is based on research funded by the National Institute for Health Research (NIHR). The views expressed, however, are solely those of the witnesses named. The research specifically concerned, in the context of medical admissions for older people with dementia, the capacity to make decisions about going home (residence capacity) and judgements about best interests for those who lacked this capacity. Our research findings are, therefore, directly relevant to House of Lords’ enquiries into the effectiveness of the Mental Capacity Act 2005 (MCA) in practice, albeit in the specific context of older adults and hospital discharge decisions. The bulk of the research took place between June 2008 and June 2009, that is, only a year or two after the full implementation of the MCA. Nonetheless, we think that our comments remain relevant. This assertion is based on clinical observations and our reading of the current literature. We would happily expand our responses if this would be helpful.

2. We shall, first, present a summary account of the evidence derived from our research and, secondly, focus on some of the specific questions asked in the Committee’s Call for Evidence. We shall indicate where responses are based on clinical observation rather than on research.

Research Findings

3. Our research involved direct observation on three general hospital medical wards in two different NHS Trusts in the North East of England. In addition, contemporaneous medical notes were reviewed and staff, people with dementia and their carers were interviewed, both on the wards and subsequently following discharge. Hence, this research was not based upon retrospective surveys or reviews of records and forms. In short, we observed the MCA being put into practice first-hand.

4. Background: A significant proportion of the hospital population has dementia and a significant proportion of people with dementia in hospital will be discharged into
long-term (residential or nursing) care. Similarly, a significant proportion of those in long-term care have come from hospital following an acute admission. Hence, decisions about residence capacity and consequent judgements about best interests are commonplace in hospitals. As the Select Committee will recognise, however, they are also of the utmost importance given the implications for human rights.

5. **The section 3 capacity test invites professionals to make value judgements which can influence the outcome of a capacity assessment:** The researcher on the ward (MP) observed and confirmed in interviews that many decisions about residence capacity are clear-cut. There is, however, a group of patients, estimated by one of the interviewed consultants to be about a third of the those seen, where the decision about capacity is complex. This is often because the person’s decision-making capacity is felt to be borderline. Our analysis is that the complexity in these cases often stems from the evaluative nature of the judgements being made. That there are value judgements in play may or may not be overt to those involved. An example would be where family, friends or professionals feel that the home surroundings are chaotic. The value judgement is whether the person’s untidiness is a manifestation of a lack of capacity or not. If a person seems oblivious of mere untidiness it could easily be argued that they can still understand, retain and weigh up information relevant to the decision. But where a house is really squalid, failure to recognise this would seem to count against the finding of capacity. A value judgement is required, however, concerning whether a house is merely untidy or actually squalid.

6. Similar value judgements can be seen to cause complexity in connection with issues around safety. The criterion of using or weighing the information is often where the judgement of value is necessary. The potential for different value judgements about the person’s ability to weigh or use information concerning safety and wellbeing were amply demonstrated in the recent case, *CC v KK and STCC* [2012] EWHC 2136 (CoP).

7. **Borderline capacity requires more complex, resource-intensive practices:** The practical point about borderline complexity is that it often necessitates, if it is to be dealt with appropriately, multiple assessments and more complex planning meetings. This is an area, therefore, with significant resource implications and where there is the possibility for poor practice if resources are inadequate.

8. **Professionals struggle to identify ‘relevant information’ during the capacity assessment process:** In connection with residence capacity, it is difficult for professionals to know exactly what would be the “relevant information” material to the decision. Although there are difficulties in connection with other decisions, they can be more straightforward (e.g. this is the treatment for X; its possible side effects are Y; its efficacy has been established as Z). Making judgements about where you live, however, can be much more emotive. Hence, professionals require more specific guidance when determining the relevant information pertinent to the specific decision being made.

9. We have suggested (see Emmett et al. 2013, attached) that patients in hospital should be assessed as unable to make a decision about where they will live after their
discharge if they are unable to understand, retain, weigh and communicate the following information:

- Why they have been in hospital;
- The social arrangements that have been proposed for them on discharge;
- The ways in which it is being suggested they will or might require help, if at all, after their discharge and the care options they would have available to them;
- Those persons and services able and willing to provide help and the nature of the help that can be provided.

Each of these points would need to be discussed with and explained to the person at the time his or her capacity was being assessed.

10. **Professionals struggled to apply a capacity ‘test’ and to adopt a functional approach to capacity assessment:** We wish to highlight two points in connection with assessment. First, many professionals find it difficult to undertake a capacity assessment as a “test”. Professionals are used to using tests for specific purposes. We surmise that the decision about whether an older person with dementia goes home or not is seen in broader terms and not as one which should routinely be based upon whether or not a person has passed a simple test of specific cognitive functions.

11. Furthermore, there was a noticeable discrepancy between, on the one hand, people’s knowledge of the criteria of capacity or incapacity and how, on the other hand, this was put into practice. This can be summarised by saying that the difference between a **functional** and an **outcome** approach to the assessment of capacity does not seem to have been grasped. In most cases, professionals or family members allowed their prediction of the potential outcome of a decision to influence their assessment as to whether or not the decision was made with capacity. To return to the example of untidiness or squalor, if a person is indicating that they think there is no harm in their returning to a house that seems excessively untidy, that alone seems to give professionals and sometimes families grounds for thinking that the person must lack capacity.

12. Our interpretation of this is that many professionals are more heavily influenced by the principles of beneficence and non-maleficence than they are by the principle of respect for autonomy. They seem, as it were, to be driven by the desire to do good and avoid harm rather than to allow the person to make unwise decisions. This, therefore, points towards what seems to be an inherent complexity in the MCA, which is that the person is allowed to make unwise decisions with capacity, but at some point the person’s apparent lack of wisdom with respect to the decision calls into question his or her ability to use or weigh information appropriately.

13. A further observation, which is a consequence of the lack of a clear distinction between the outcomes-based or functional type of assessment, is that where a person’s decision agrees with that of professionals or family and other carers, it is less likely to be questioned; whereas when the person’s decision does not accord with those of others, capacity is more likely to be assessed and more likely to be
found wanting. Our research further demonstrated that a finding of lack of capacity seemed likely to increase the chances of placement in long-term care.

14. **Documentation varied in quality and detail:** We found that there were significant differences in terms of the content and quality of relevant documentation. Assessments of capacity and judgements about best interest were summarised in brief single sentences, or recorded in much more detail. Some people used pre-prepared forms. There is a great variety of such forms. Even when they are completed, however, they do not always provide the detailed information that might be required to demonstrate either capacity or its lack. For instance, in response to a question on a form about the person’s ability to weigh or use information, a clinician had simply written “yes”.

15. Health and social care workers were very clear that documentation needed to be good, especially in connection with residence capacity where there was the potential for Deprivation of Liberty. But in the business of an acute medical ward careful record keeping, as would be required in a Court, about capacity and best interests is difficult to achieve. As a specific example, best interests is not assessed or judged in a way that shows a grasp of the Code’s checklist and is certainly not recorded in a formal way, perhaps reflecting an ignorance of the existence of the best interests checklist.

16. **Understanding a person’s narrative is a vital prerequisite to assessing capacity and determining best interests:** We shall confine ourselves to two points. First, there is a question about which or whose narrative has authority. Our observation was that the person with dementia was frequently ignored: hence, the story told by the person most concerned by the decision was often not heard. Thus, for instance, although it was routine for family members to attend multidisciplinary team meetings, the person with dementia attended much less frequently. Bearing in mind the potential for decisions to be influenced by a predicted outcome, the narrative of a neighbour who had seen some risky behaviour at some point in the past might, once recorded in the clinical notes, turn out to be very influential both in terms of the assessment of capacity (if the person could not remember the behaviour that was described, then their capacity might be doubted) and best interests (the story of risky behaviour might well incline the health and social care team to think that independent living was no longer in the person’s best interest).

17. Secondly, in connection with narrative, the role of the decision-maker becomes crucial. In the wards on which we observed, the *de facto* decision-maker was the medical consultant. But we know of other areas where these decisions about patients will often involve the Social Worker as the decision-maker. On the other hand, *de jure* the decision-maker could be a member of the family. Outside hospital, we presume that family members will often make decisions about residence for ageing parents. A general problem, therefore, is that the MCA lacks sufficient independent procedural safeguards to monitor how residence capacity assessments and judgements about best interests are made in practice. Instead, professionals are largely self-governing in their role. Meanwhile, families often feel ill-prepared and ill-equipped, without support, when it comes to their involvement in multi-professional meetings to make decisions about their loved one’s place of residence. We tend to think,
therefore, that the role of the IMCA service should be expanded in order to provide appropriate support not just to those who lack the support of family and friends, but also for the families and friends themselves who otherwise would seem to lack the detailed knowledge and expertise that the IMCA provides to someone who is “unbefriended”.

18. **Time and timing of capacity assessments is critical to good practice**: The issues of time and timing can be dealt with very briefly. As we have already suggested, residence capacity can be quite complex to assess as can judgements about best interests with regards to place of residence and, therefore, a good deal of time may be required in order for these assessments and judgements to be undertaken properly. We are suggesting that step-down or rehabilitation units will often be required for the more complex cases in order to allow the appropriate time to be taken.

19. In addition, the timing of assessments is obviously crucial. Assessments undertaken too early in an admission may well occur when the person is still suffering from elements of an acute confusion (that is, a delirium). The reality, again, is that discharge decisions may have to be delayed until it is clear that the person is in a fit enough state to be assessed properly for residence capacity.

**Specific questions (in bold, with numbers in square brackets, from the Call for Evidence)**

20. **To what extent has the MCA achieved its aims?** [1] As with a number of oral witnesses, we would agree that the MCA represents good and worthwhile legislation. On the whole, however, we are slightly more inclined to side with Professor Richard Jones in expressing some doubts about the extent to which the principles of the MCA have been thoroughly embedded in practice. We would tend to agree with Toby Williamson that the Act itself does not require significant change, but that all those affected by the Act should understand how it relates to their policies and processes. In clinical and social care practice the language of the Act is established. This often simply translates, however, into the requirement that a particular form should be used without real appreciation of its implications. So the Act has achieved some of its aims, but needs deeper embedding.

21. **Which areas of the Act, if any, require amendment and how?** [2] As we suggest above, the role of the IMCA might require expansion in order to provide the same sort of expertise and knowledgeable support, not just to people who are unsupported by families, but also to the families themselves in order to help them through the process of decisions about patients. It may be that greater attention is given to the Code of Practice. The Code of Practice, for instance, could help to drive home the point about the difference between a functional and an outcomes approach to capacity. We have also suggested that more guidance is needed for professionals properly to identify what is ‘relevant information’ when assessing residence capacity, and have suggested some specific information that a person might be reasonably required to understand, retain and use, as well as communicate, in making a decision about place of residence in order for it to be said that he or she has capacity. Such criteria could reasonably be set out in the Code of Practice. We also believe that, in complex decisions such as those to do with place of residence, there needs to be more guidance on who should be the decision-maker.

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22. **At the core of the MCA are its principles and definitions of capacity and best interests. Are these appropriate?** [3] Yes, largely we believe that the principles and definitions are good and useful. However, the concept of a capacitous unwise decision remains difficult for practitioners and may require further clarification in the *Code of Practice*.

23. **To what extent have the five principles of the MCA been implemented in frontline practice?** [4] We think, on the basis of both research and clinical experience, that the broad principles of the MCA are generally understood, even if implementation and the depth of understanding of the principles vary markedly. In connection with place of residence, however, it is not entirely clear that the principle of choosing the least restrictive option is given as much weight as it could be. This is because of broader social concerns about safety. There are also resource implications in that to allow someone to go home to live independently may require an extensive care package. We can sometimes see, as practitioners, a lack of equity in terms of the provision of support and care in the community for some types of patient over against others. For instance, for almost all people with dementia, 24-hour care in their own home is out of the question. Yet, this occurs for other patient groups. If the principles of the MCA were to be fully implemented, 24-hour care in the person’s own home should be more common, but the resource implications seem to be prohibitive.

24. **Is the Act widely known and understood by professionals required to implement it?** [6] We think that the main principles of the Act are widely known but implementation differs. For instance, in our research we noted that certain professional groups, for instance, Old Age Psychiatrists and Social Workers, were more likely to record assessments of capacity and best interests in more detail than some other professional groups.

25. **Is the Act widely known and understood by those who are directly affected by it and by their non-professional carers?** [7] We have indicated above that families need more support, in particular in connection with residence capacity. Many of them will not understand the law and will not understand the procedures involved, so they are significantly disadvantaged in terms of their ability to participate effectively in decision-making and meetings about decision-making.

26. **Has the Act ushered in the expected, or any, change in the culture of care?** [8] There have been beneficial changes, as shown by the language that people use. People often (but not always) recognise that the issue is one of capacity and, where that is lacking, of best interests. But, it could more cynically be said that the biggest cultural change is that people feel it necessary to fill in more forms. Meanwhile it seems, clinically at least, that whether or not people with dementia go into long-term care depends more on Local Authority funding than on the implementation of the MCA. It may be, as Toby Williamson argued, that more work needs to be done to help people to recognize the importance of the MCA. It seems apposite to quote Martin Luther King speaking on 13th November 1967 when he received his Honorary Doctorate of Civil Law from Newcastle University: “And so while the law may not change the hearts of men, it does change the habits of men if
vigorously enforced, and through changes in habits, pretty soon attitudinal changes will take place and even the heart may be changed in the process”.

27. **Are those directly affected by the Act being enabled and supported to make decisions for themselves to a greater or lesser extent than they would have been in the past?** [10] Our observation that the person with dementia is fairly frequently not involved in decisions about where they should live tends to suggest that the Act has not been successful in this regard. We guess that the Act may have increased the tendency for people to be enabled and supported to make decisions for themselves in some areas of practice but not in others.

28. **Question 10 goes on to ask about the means by which decisions are made.** As a purely clinical observation, we would note that we are occasionally asked to fill in documentation from the Court of Protection (e.g. CoP Form 3) on the grounds that the person lacks capacity to manage their finance and property or to make welfare decisions. Under these circumstances, however, it often appears that no one has considered the capacity to complete the appropriate Lasting Power of Attorney (LPA) forms. The test of capacity to complete a LPA is not as well defined, we believe, as the previous test to complete an Enduring Power of Attorney (EPA). Nevertheless, intuitively it would seem that the level of capacity required to sign the LPA forms must be lower than the level of capacity required actually to manage complex financial decisions or to make important decisions about welfare. The tendency for Solicitors to direct people immediately towards deputyship and the Court of Protection rather than to consider the capacity to complete a LPA needs, in our opinion, to be highlighted and corrected.

29. **What evidence is there that advance decisions to refuse treatment are being made and followed?** [11] Advance decisions to refuse treatment are becoming more common, but they remain relatively uncommon in the older population. In particular, in people with dementia advance decisions to refuse treatment remain rare (see Robinson *et al.* 2012, attached).

30. **Has the MCA fostered appropriate involvement of carers and families in decision-making?** [12] Again, although carers and families are not infrequently involved in decisions about finance, which partly reflects the previous familiarity with EPAs rather than any change brought about by the MCA, it remains relatively uncommon for families to have a LPA that covers health and welfare decisions in older people with dementia. We are unaware of any evidence that the MCA has fostered an increase in terms of involvement of carers and families in decision-making generally. It is our experience that carers and families were already previously involved in decision-making about place of residence. Yet the depth of current involvement remains patchy.

31. **Has the role of the IMCA succeeded in providing a voice for clients and an additional safeguard against abuse and exploitation?** [13] Our research included an interview with an IMCA. The benefit of an IMCA’s involvement is that a more detailed case about best interests is made. From a clinical perspective, however, rather than on the basis of research, we are unaware of decisions which would have been otherwise had it not been for the involvement of an IMCA.

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32. **Concerning the Deprivation of Liberty Safeguards (DoLS)** [16 and 17] Our research did not specifically consider DoLS, but was obviously relevant to it. From clinical experience, however, although DoLS are often spoken of, we have fairly infrequently seen them put into effect. Our impression is that the DoLS system is overly bureaucratic and not particularly effective. Underpinning our concerns is the conceptual point that the notion of “Deprivation of Liberty” is not well grasped in connection with the ordinary everyday care of people with dementia who would require at least a restriction of their liberty under any circumstances.

33. **What has been the impact of the introduction of Lasting Powers of Attorney (LPA)?** [19] Really very few LPAs in connection with personal care and welfare seem currently to be in use by the present cohort of people with dementia. We neither came across LPAs for welfare during our research, nor are they common clinically even if they may be increasing.

34. **What concerns, if any, are there regarding the costs associated with registering an LPA etc.?** [20] Again, this is beyond our research, but our clinical observation is that the costs associated with LPAs have tended to make them less accessible than the previous EPA. The process itself seems more cumbersome.

35. **How well is the relationship with the mental health system and legislation understood in practice?** [24] We cannot comment directly on this on the basis of our research, but from a clinical perspective we would endorse the earlier comments that you heard from Professor Richard Jones (summarized in his answer to question 1 on Tuesday, 25th June 2013).

2 September 2013
Human Tissue Authority – Written evidence

Executive Summary

1. This evidence is submitted on behalf of the Human Tissue Authority (HTA). The HTA’s view is that the Mental Capacity Act 2005 provides clarity as to the approach to be taken when dealing with adults without capacity. However, less clarity exists for: a) dealing with adults who may not have capacity and b) the consent of children who are being medically assessed and prepared as bone marrow or peripheral blood stem cell donors. Greater clarity and guidance in the Mental Capacity Act’s accompanying Code of Practice would assist in managing these cases.

2. Clarity would also be welcomed on the law on consent for brain donation after death, on behalf of someone who is alive but who does not have capacity to give consent themselves, for example, in cases where people have dementia.

The Human Tissue Authority

3. The Human Tissue Authority (HTA) is a regulator established in 2005 to ensure human organs and tissue are removed, stored and used only when consent is in place. The legislation that established the HTA not only addressed this issue, but also updated and brought together other laws that relate to human tissue and organs.

4. The HTA regulates organisations that remove, store and use human tissue for research, medical treatment, post-mortem examination, education and training, and display in public. The HTA also gives approval for organ and bone marrow donations from living people. The HTA provides advice and guidance to our regulated sectors and shares knowledge and experience gained from regulation to help licensed establishments better meet HTA quality standards.

5. The HTA was created by Parliament via the Human Tissue Act 2004 as an executive non departmental public body of the Department of Health, and is overseen by an Authority of lay and professional members appointed by the Government. The Human Tissue Act 2004 covers England, Wales and Northern Ireland.

6. The interests of the public and those the HTA regulates are central to our work. The HTA builds on the confidence people have in our regulation by ensuring that human tissue and organs are used safely and ethically, and with proper consent.

7. There are many different types of human cells and tissue which the HTA has a role in regulating the removal, storage and use of, including skin, body parts, organs, and bone. Bodies, organs, tissue, and cells can be used for many purposes including:

- treating patients with particular medical conditions;
- transplanting into people whose organs have failed;
- treating patients who have blood disorders like leukaemia with stem cells;
- researching causes and treatments for illnesses, such as cancer or diseases of the brain and nervous system;

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• teaching students about the human body and training them to develop the skills of surgeons;
• display in public, such as exhibitions and museums;
• finding out through post-mortem examination why someone has died, including examining their organs and tissue samples to determine the cause of death.

8. An independent survey commissioned by the HTA showed that patients and families have more confidence that their wishes will be respected if they know there is regulation of human tissue and organs. Regulation also means that organs and tissue used in treatment will be safe and high quality; and that tissue used for research or other purposes will be put to the best use possible.

9. By fostering an environment of trust, the HTA hopes people will be confident to donate their tissue for scientific and medical research, their organs for transplants, and their bodies for medical education and training. On that basis, the HTA can support healthcare and research in the UK and further afield.

**The HTA’s role in organ donation**

**Organ transplantation**

10. Organs – including kidneys, liver, lung and pancreas – are transplanted into patients to save and improve their quality of life. The HTA does not promote organ donation. That is the role of NHS Blood and Transplant (NHSBT). The HTA licenses establishments, and does not regulate individual clinicians or healthcare professionals.

11. The HTA regulates, through an independent assessment process, the donation of organs from living people across the UK and bone marrow and peripheral blood stem cells from children and adults who lack the capacity to consent. The HTA works to ensure that valid consent has been given by the donor so they fully understand any risks, donate of their own free will and that no reward is associated with the transplantation. Annex A to this document sets out the procedure which is adopted.

12. In 2012/13 the HTA assessed 1243 living organ donation cases and approved 69 bone marrow and peripheral blood stem cell cases.

**The HTA’s interaction with the Mental Capacity Act 2005**

13. The HTA’s interaction with the Mental Capacity Act 2005 arises in the work to ensure that valid consent has been given by the donor so they fully understand any risks, donate of their own free will and that no reward is associated with the transplantation.

14. The Mental Capacity Act 2005 provides some clarity as to the approach to be taken when dealing with adults without capacity but it is not always clear as to the right approach with adults who may not have capacity to make a decision at a specific time on a specific topic (see the example referred to below in paragraph 15). Less clarity also exists for dealing with the consent of children who are being medically assessed so that they can be bone marrow or peripheral blood stem cell donors (see the example set out in paragraph 16). The HTA has a unique role as living donors undergo major surgery for no physical benefit to themselves. In fact they face certain risks in order to help someone else.

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Therefore, the responsibility to ensure the right person is giving consent and that the consent is informed and freely given by a person with the capacity to do so, is central to the HTA’s work.

15. For example, the HTA has assessed cases where the initial report of the interview with an adult organ donor has explained that the donor was unable to recall any of the risks associated with the procedure or what kind of operation it would be (open or keyhole, for example). These are both statutory requirements and therefore the HTA corresponded with the clinicians treating the donor and asked them to have a follow-up discussion on these matters and provide the information necessary for the donor to understand them on their own terms. On occasion this discussion has had to take place more than twice before the donor could retain the information. It is not clear when a decision should be made to move to an assessment of capacity in such cases as this could merely be forgetfulness on the donor’s behalf, or more seriously an inability to assess information and make an informed choice.

16. In contrast, another example would be of a child aged 12 being medically assessed to enable them to donate bone marrow to a younger sibling. The Human Tissue Act 2004 (Persons who Lack Capacity to Consent and Transplants) Regulations 2006 require that an interview is conducted with the donor and the HTA is to assess the case only where the donor is a child who lacks competence or an adult who lacks capacity to consent. A small number of such cases have caused the HTA concern as the 12 year old (for example) has stated they do not wish to donate, but the treating clinicians have stated that the child does not have competence to consent and it is the person with parental responsibility from whom consent should be sought. It is often the case that the child has articulated their fears and views very clearly and on paper it is not easy to establish their lack of competence.

17. Further guidance would be useful to assess competence in these circumstances, including the interaction any such assessment would have with the Children Act 1989 and assessing Gillick competence (the case of Gillick v West Norfolk and Wisbech Area Health Authority 1986 1 AC 112 where the court found that a child below 16 years of age will be competent to consent to medical treatment if they have sufficient intelligence and understanding to make decisions regarding their own healthcare), particularly with teenage children below 18 whom are able to articulate their views. Guidance would also be useful as to the position in Scotland, as the concept of Gillick competence does not exist in Scottish law whilst the HTA’s remit includes Scotland by virtue of the Human Tissue (Scotland) Act 2006.

18. The HTA has noted the Welsh Government’s inclusion of a definition of a child’s competence to consent in the Human Transplantation (Wales) Bill and will follow with interest whether this gives clinicians more confidence when working with children on the cusp of competence.

Regulating research

19. Human tissue can be studied to improve the understanding of health and disease. The HTA aims to support good research in the UK. The HTA believes that good regulation supports good science, which in turn leads to improved healthcare.
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submissions.
Chief Executive, Human Tissue Authority

August 2013

Annex A

Overview of Human Tissue Authority living donation approval process

Potential living donor identified: medical assessment and work up by transplant unit

Donor clinician refers case to HTA Independent Assessor (IA)

Independent Assessor interviews donor and recipient (separately and together) and submits report on case to HTA

Child or adult lacking capacity
Non-directed altruistic
Paired / pooled
Novel transplants
Directed altruistic

Directed cases

Further information / clarification sought from IA if required

Case assessed by HTA panel

Case assessed by HTA Transplant Approvals Team

HTA decision

30 August 2013

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
The IMCA Service in Rochdale and District Mind – Written evidence

The IMCA Service in Rochdale and District Mind – Written evidence

The IMCA service in Rochdale would like to submit the following evidence:

Overview and context

1. It is a step in the right direction but there is a lack of training generally and consequently a lack of awareness.
2. The IMCA remit needs to be expanded to cover finances, other than in safeguarding cases. There needs to be more of a role around finances.
3. Definition of capacity needs to be clearer.

Implementation

4. Training is an issue, particularly in hospital settings. There is too much emphasis on protection and not enough on enablement. Funding can get in the way of enablement. There is a lack of checking/monitoring with Court of Protection Deputyship for finances.
5. There is a lack of available information and a lack of training for members of the public. The information available is patchy. Needs a national campaign.
6. Even health and social care professionals don’t always understand MCA so it is unlikely that bankers and others have a good knowledge.
7. No – see above.
8. Residential homes are generally more aware of MCA. There has been some change but a way to go yet.
9. From our experience our cases are predominantly from white british population even though we are in an area with a high ethnic minority population.

Decision Making

10. Yes, by virtue of having IMCAs. You would expect it to be better because there is a structure. Not every case makes it to the court of protection due partly to cost.
11. Very little evidence of use in our area.
12. Yes, if best interests process followed it should include family.
13. Yes
14. We have high levels of referrals due to our awareness training and networking. Neighbouring authorities appear to have fewer resources and fewer referrals.
15. We are better resources relatively speaking than some areas but are probably still under resourced. There is room for improvement with the qualification and there is a lack of access to training which is mainly in London. Refresher training would be good.

Deprivation of Liberty Safeguards

16. Yes
17. Authorisation and review are timely. Challenge is a slow process as is anything involving solicitors.

The Court of Protection and the Office of the Public Guardian

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
The IMCA Service in Rochdale and District Mind – Written evidence

18. No and No
19. There was a slow start with few applications but applications are becoming more frequent.
20. Cost can put off some people from applying, particularly if they also need to use a solicitor to complete the forms.
21. Emergency legal aid is limited. Legal aid is only available to those with no capital. Recent reforms mean even fewer people will qualify.

**Regulation**

22. CQC inspections need to be more robust and thorough and CQC itself needs to be better resourced to allow them to do this.
23. ?
24. Not very well

21 August 2013
The Institute of Professional Willwriters (IPW) is a membership organisation formed in 1991 and represents 900 people working in 265 firms who specialise in drafting Wills. A large number of our members are involved in drafting and registering Lasting Powers of Attorney (LPA) and it is this aspect of the MCA that the IPW and its members have most interest in and to which we would like to respond to the Call for Evidence by the Select Committee.

1. To what extent has the Mental Capacity Act 2005 achieved its aims?

A significant reason given for replacing Enduring Powers of Attorney (EPA) with the LPA under the MCA was that there was perceived to be a large scope for abuse by attorneys acting under an EPA. We have never really understood how the changes made by the implementation of the LPA were ever intended to limit the scope for abuse and note that there have been cases reported where attorneys have been convicted of abuse while acting under the authority of a registered LPA.

The reality is that it is just as easy for an attorney to coerce a vulnerable person into giving them powers under an LPA as it ever was under an EPA.

We believe that the issues are:

An LPA requires notice of its registration to be given to up to five named persons. Is there ever a check that such named persons are actually notified? We are not aware of such checks.

An LPA requires a person who claims to have known the donor for at least two years or claims to have professional skills to provide a certificate to the effect that the donor understands the document and is not being coerced into making it. Two such certificates are required if the donor elects not to name a person to be notified of registration. In reality this process provides no safeguards at all. Is there ever a check on the actual credentials quoted by the certificate provider? We are not aware of such checks.

An LPA is required to be registered before it can be used. Other than a revenue generating exercise, does the registration provide any useful abuse or deterrent to fraud? We are unable to identify any useful checks made during the registration process that would identify and stop the registration of a fraudulent LPA.

The length of the document, running to many individual pages is a risk to fraud. An attorney intent on committing fraud under an LPA could easily prepare a document which looks sensible and get the donor to sign it. It would then be easy for a deceitful attorney to prepare a second LPA which more accurately reflected their intentions and insert the page signed by the donor into it and submit it for registration.

The length of time that it takes to register an LPA (currently 9 weeks) means that an LPA can never be created for ‘emergency’ use. We suspect that a significant number of donors die before the registration of their LPA has been completed.
We therefore believe that the MCA has missed its aims in relation to the implementation of Lasting Powers of Attorney. Arguably it is now easier to commit fraud under an LPA than it was under an EPA. At least under an EPA the people to be notified of registration were family members set out in the relevant legislation – not people chosen by the donor – or by an attorney intent on committing fraud.

2. Which areas of the Act, if any, require amendment, and how?

We would like to see the following changes made to the provisions on LPAs:

- A check by the OPG during the registration process that the named person(s) have actually been notified of the intention to register the LPA.

- The certificate should only be provided by someone entirely independent from the donor. This person needs to have good understanding of LPAs and also the issues surrounding the capacity of a donor to make such a document. This might be some doctors, but not all doctors. It might be some lawyers, but not all lawyers. It might be some in the voluntary sector, but not everyone who works in the voluntary sector. It’s therefore difficult to categorise who might be competent to provide a certificate by their job description. We favour the compilation of a register of certificate providers, held by the OPG and published on their website (where the LPA forms can be downloaded). The register should be limited only to those people who apply and who can prove that they have experience or expertise in LPA’s and capacity issues.

- Options to reduce the number of pages in the document – such as the omission of pages that are irrelevant to the working of the LPA. Also the option to produce documents that only contain the relevant information without having to comply with the straight jacket requirements of the prescribed forms. The legislation under which EPAs existed made provision for both of these options. The legislation in Scotland on the equivalent Continuing Power of Attorney also does the same, where no prescribed form is set out.

- A requirement that each and every page of a multi-page document should be signed by the donor.

- We still support mandatory registration of an LPA before use but would like to see alternative procedures based on risk. For example when a donor appoints all of his children as attorneys, is there any value in delaying registration, waiting for the period to lapse in which a named person (possibly from outside of the family) can object to registration An option for the named person to declare that they have no objections to registration would also be helpful in reducing registration waiting times.

19. What has been the impact of the introduction of Lasting Powers of Attorney, especially with regard to decision making on matters of personal care and welfare.

Our members report that the number of LPAs that they draft has stayed roughly the same as it was when EPA’s existing, or else has dropped. We acknowledge that more donors may be drawing up LPA documents through online and download forms and that may impact on the decline in documents being produced which has been reported by some professionals.
However cost, not only of registration, but in relation to the additional work involved in drafting a document which is substantially more involved than an EPA is likely play its part. Exemptions and remissions from registration fees will come to the help of some (but not all) but the elderly and vulnerable are groups least likely to be able to draw up their own documents from the internet and thus more likely to incur document drafting fees.

The number of Health and Welfare LPA’s drawn up by our members is negligible. Again cost (double the drafting and registration costs of drawing up single document) is a huge barrier. Some of our members recommend an Advance Decision as a cheaper alternative to a Health and Welfare LPA.

Ever since the early days of conception of the LPA, the IPW has championed the idea of an option of combined, single document for both personal care and financial matters – especially where the attorneys would be the same for both matters. We understand that this concept is finally being considered. It can’t come soon enough if more attorneys for personal matters are to be appointed.

20. What concerns, if any, are there regarding the costs associated with registering an LPA, or with making an application to the Court of Protection?

Cost of registration of a document, when added to the cost of a professional drafting the document can be a problem. For example, a couple drawing up both types of documents could face registration fees of £520 (until 1st October 2013) and professional drafting fees of the same or more.

Members report that frequently their clients elect to have an LPA document drawn up but elect to leave registration until such time as the attorneys may actually need to use it. The only practical problem with this is that the lengthy registration process will delay the implementation of the document if it is not registered early enough.

A less bureaucratic registration process and the use of technology to introduce efficiencies with the aim of bringing the fees for registration to point where they become a negligible amount should be encouraged.

21 August 2013
Irwin Mitchell LLP – Written evidence

Irwin Mitchell is the leading Court of Protection law firm in England, with over 75 employees specialising in this field, and has a pre-eminent reputation for Court of Protection services. It is the only tier one listed firm in both Chambers and Legal 500 directories.

Irwin Mitchell is a national firm, with offices in eight cities in England, handling all aspects of Court of Protection services, whether relating to property and affairs or health and welfare. Irwin Mitchell’s Court of Protection team handle many complex high value financial cases involving multi-million pound funds. The Court of Protection team are members of the Panel of Court Appointed Deputies, the Deputy’s Forum and the Joint Liaison Group of the Court of Protection.

Irwin Mitchell’s Public Law team regularly act in complex Court of Protection litigation, with cases involving issues such as capacity to have sexual relations, right to die/right to life cases, complex serious medical treatment and welfare disputes.

We have acted for a party in the majority of the leading reported cases in the Court of Protection and have also acted in a number of cases in the field prior to the implementation of the MCA. We have organised many seminars and our lawyers have spoken at many seminars across the country, which are attended by a range of practitioners and lay people.

This submission is made jointly by Irwin Mitchell’s Court of Protection and Public Law departments who together provide the above full range of Court of Protection services to the public.

Summary of submissions

- The MCA has broadly achieved its aims of codifying the law of mental capacity and raising knowledge and awareness of the issues surrounding decision making for those who lack capacity.
- However, there is still a general lack of awareness/understanding of the MCA among the public at large and among professionals outside the legal and care professions.
- In our experience awareness and appropriate application of the MCA is better among social care professionals than it is among health care professionals.
- Common problems in the application of the Act include a lack of emphasis on the need to assist individuals to make capacitous decisions and a failure to properly involve friends and family members in the best interests decision making process.
- The DOLS regime is too complex and is not sufficiently clear, accessible or timely.
- There is often little knowledge in the police and banking sector to the powers of the Court of Protection to make orders under the MCA to protect an individual from financial or other abuse. There is potential to enhance the knowledge in this area by including in all local safeguarding policies, reference to these protection powers and guidance on when to refer cases for an application to the Court of Protection.
- IMCAs carry out a vital role in standing up for the rights of those who lack capacity. However, their independence should be protected by removing from local authorities the function of commissioning IMCA contracts. Guidance is also needed on how IMCAs can bring matters to the attention of the Court of Protection where appropriate.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
• Means tested legal aid remains available in welfare cases. However, non-means tested legal aid ought to be available to families involved in very serious cases affecting the individual’s right to life or their proposed removal from the family home by the state.

• The Court of Protection rules ought to be strengthened in cases of health and welfare. Where a state body has failed to bring a dispute, over a legitimate medical treatment dispute or dispute affecting P’s Article 2, 3 or 8 rights, before the court and another party brings an application before the court to resolve the said dispute – the presumption should be that the state body bear the costs of bringing such an application.

• Serious consideration should be given to the regionalisation of the Court of Protection, as has been done with the Administrative Court.

**Overview and context**

To what extent has the Mental Capacity Act 2005 (MCA) achieved its aims?
The MCA has broadly achieved its aims of consolidating the fields of financial and welfare decision making for those who lack the requisite capacity. The MCA has also succeeded in codifying the pre-existing common law welfare jurisdiction, and in doing so has greatly raised awareness of the law in this field, although for the reasons set out below, there is still some way to go in raising awareness.

Which areas of the Act, if any, require amendment; and how?

We have seen, and been involved in drafting, the submissions made by a group of MCA practitioners led by Alex Ruck Keene of 39 Essex Street Chambers. We agree with the views expressed in that submission in relation to s.44 MCA, Schedule 1A and Schedule 3. The opaque drafting of Schedule 1A in particular causes great difficulty when advising clients on the inter-relation between the MCA and the Mental Health Act. We have seen it cause medical and social care practitioners difficulty in understanding the inter-relation.

We would suggest an additional principle to the Act, to the effect that any uncertainty over, or dispute in relation to, a person’s capacity must be resolved as quickly as possible.

Additionally, as set out below, we consider that s.4(7)(b) MCA requires amendment in order to highlight the need for friends and family to be consulted as part of the best interests decision making process.

We also consider that the responsibility for commissioning IMCA services needs to be taken away from local authorities and given instead to an independent body, for the reasons set out below.

Finally, we consider that there is a need for formal and practical guidance on how IMCAs can bring matters to the Court of Protection where appropriate.

At the core of the MCA are its principles and definitions of capacity and best interests. Are these appropriate?

One of the difficulties with principles is that they are succinctly stated, but in our experience the Code of Practice that expands upon their meaning is rarely read, even by social workers, GPs and other practitioners. This leads to the principles sometimes being misunderstood.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
By way of example, the first principle that ‘a person must be assumed to have capacity unless it is established that he lacks capacity’ is appropriate in theory, but in practice from our experience this is often interpreted (it must be said when convenient to do so) by local authorities in particular to assume someone has capacity but without taking the principle to the logical next step which is to obtain an assessment when it is not clear and/or there is a dispute as to whether P has capacity. It can therefore be used as an excuse to do nothing on the basis of someone being a conscientious refuser of services, on the basis that P is expressing a view and ‘they must be assumed to have capacity’.

As just one example, we are involved in a case at the moment in which for a number of years concerned family friends have attempted to resolve disputes about the care of an individual. They have always been refused access to records and attempts to increase care have been rejected on the basis that the individual was asked whether she wanted more care and said she did not. No assessment of capacity was undertaken and it has taken threats to go to the Court of Protection even for the local authority to carry out its own capacity assessment.

There is also a lack of clarity if there is a dispute as to who needs to take responsibility to obtain a capacity assessment, which individual will do the assessment and who will pay for it.

We would therefore suggest an additional principle to the effect of ‘Where it is not clear if a person has capacity (to make the relevant decision) or there is a dispute as to a person’s capacity, attempts must be made to establish whether they have capacity as quickly as possible.’

We agree with the principle that ‘a person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success’.

The principle that ‘a person is not to be treated as unable to make a decision merely because he makes an unwise decision’ is in our experience the most controversial of principles, particularly amongst parents/carers of young adults who would wish to see more protective measures put in place to safeguard their family members. Often disabled people themselves however take a different view and believe that they should be allowed to take ‘unwise’ (sometimes risky) decisions. At the seminars we host this is usually the subject of much debate, but we nevertheless are of the view that the principle is appropriate – the issue is the understanding of practitioners as to how it is applied.

We agree with the principles that ‘an act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests ’and that ‘before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.’

We consider the definition of capacity to be appropriate, although the quality of assessments is highly variable. We would like to see greater emphasis on capacity being issue specific, and the need to properly engage with the individual in order to establish whether they have capacity in each specific area. Too often we see capacity assessments that have far too little detail in order to establish, for example, whether the person is able to weigh up the pros and cons of a decision. We consider that the COP3 form should be amended to make it clearer that capacity is issue specific.
We agree that the term best interests is not defined in the act, but we have concerns that the test for how to make a decision in someone’s best interests does not sufficiently highlight the role of parents/carers or other close family and friends.

Our experience is that family members are very often excluded from the best interests decision making process, and we have prepared precedent letters in conjunction with national charities; Mencap, the Challenging Behaviour Foundation and Ambitious About Autism (annexed to this response) which seek to address this specific concern. This can be due to a complete lack of knowledge about the Act – we regularly hear examples of where someone is told that because an individual lacks capacity, a decision can be taken for them without any understanding that this needs to be done in a collaborative way.

We think that the provision contained within s.4(7)(b) MCA that a decision maker ‘...must take into account, if it is practicable and appropriate to consult them, the views of ... anyone engaged in caring for the person or interested in his welfare’ should be given far greater prominence. This provision should be amended to make it clearer that friends and family are included within this definition.

**Implementation**

To what extent have the five principles of the MCA been implemented in frontline practice? What evidence is available to assess this? Is there a satisfactory balance between enablement and protection?

Our impression is that those working in the social care arena have a better awareness of the MCA than those working in the health care arena. Implementation of the principles of the MCA is thus better in the social care field. Those working for local authority social services departments are generally aware of the act and of its principles, although some aspects of the MCA are better understood than others, and there is often a tendency to apply the principles of the Act in a selective way in order to reach the outcome that suits the local authority. In particular, as set out above, we consider that there continues to be insufficient emphasis placed on the need to consult friends and family as part of the best interests decision making process.

It would seem that medical professionals are far less knowledgeable about the MCA than social care professional. This may be as a result of a general lack of awareness, lack of training, the lack of availability of legal advice (as a consequence of the lack of an in-house legal departments within NHS trusts), or resistance to change.

This general lack of knowledge amongst the medical profession also extends to the approach taken in assessing an individual’s capacity to make decisions on medical treatment. From our experience, capacity assessments conducted by responsible clinicians often lack clarity and detail with regard to the reasons for conclusions reached as to whether the individual does or does not have capacity in the relevant areas. All too often capacity assessments are carried out which fail to apply the principles of ss.1, 2 and 3 MCA in any meaningful way, if at all. Furthermore, too little attention is paid to the need to support people so far as possible to make their own capacitous decisions.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Our experience has also shown that, again generally speaking, the police have very little, if any, knowledge of the MCA and the Code of Practice. This is alarming given that the police will often be involved in adult safeguarding cases. This has particular relevance to the issue of conducting Achieving Best Evidence (“ABE”) interviews for the purpose of obtaining sufficient evidence for a prosecution. Case law within the Court of Protection has specifically dealt with this point and requires the police to inform the individual’s litigation friend, where Court of Protection proceedings are already ongoing, that they seek an ABE interview and will be making an application to the court. In our experience, there would appear to be a general lack of knowledge of this requirement, and also general reluctance on the part of the police to make applications to the court, either for disclosure of evidence, permission to forensically examine or for an ABE interview.

How effective was the Government’s implementation plan? What measures were taken to ensure that professionals and families of those who lack capacity know about and act in accordance with the provisions of the MCA? Has it led to sustainable change?

Training in the MCA appears to have been better in the social care domain than in that of health care. Knowledge of the MCA appears to be poor among the public at large, which is perhaps not surprising given that information for the public is likely to come from health and social care professionals, who in turn are not as well informed about the Act as they could be.

Is the Act widely known and understood by professionals required to implement it? How does this differ across different sectors, such as health, social care, banking and others?

Our view is that the Act is not always widely known and understood by professionals required to implement it. Generally, health care professionals have a much weaker knowledge and awareness of the MCA than their social care counterparts. Their capacity assessments are often less thorough and less compliant with the MCA.

Generally, in the social care sectors there is evidence that professionals have been trained on the MCA implementation and as a result their understanding is greater. However, lay deputies do not receive any training on the Act and its implementation and the information they receive from Court is perhaps insufficient to enable the Act to be implemented fully and in the client’s best interests.

In the banking arena, we experience serious problems with many banks and individuals not even knowing what a deputy is. This in turn makes it very difficult to assist and empower our clients to manage their monies. Even where they do, commercial concerns of dealing with persons who lack capacity can result in unfair treatment in relation to bank accounts and slow and cumbersome delays whilst referrals are made to centralised in house legal departments.

From working alongside the police in the Court of Protection we have the impression that the police do not understand the Act. This can make it difficult for example where the Orders give permission for the police to return an individual to a place of safety. It is also disappointing that although the MCA contains provisions in relation to financial abuse, the police are reluctant to bring action because of concerns about the ability of a protected person to give evidence.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
There is often little knowledge in the police and banking sector to the powers of the Court of Protection to make orders under the MCA to protect an individual from financial or other abuse. There is potential to enhance the knowledge in this area by including in all local safeguarding policies, reference to these protection powers and guidance on when to refer cases for an application to the Court of Protection. There is also a lack of knowledge about the ability of the Court to be flexible and responsive, with the ability to make access judges to make urgent orders at short notice and out of hours where necessary.

There can often be a reluctance in professionals referring the case for an application to the Court of Protection because of a lack of confidence that there will be the resources and time to manage such a case. Often such lack of confidence is misplaced and places P at risk of harm or potential abuse. We have been involved in a case where an adult living in the community, in his own home was being targeted by a group which sought to abuse him financially and physically. The group also targeted his home and caused damage to it. Local safeguarding processes were slow to progress over a number of months. Despite the local authority, mental health services and police all being involved (one meeting involved more than 10 publically funded officers of the police/council/NHS), none were able to take positive action by way of an application to the Court of Protection to obtain orders under the MCA to protect P. There was little or no knowledge of the ability of a judge of the Court to grant injunctive orders protecting P and (in P’s best interests) making orders placing a ‘no contact exclusion zone’ against known individual abusers around P’s home. Eventually a non state party made the application to the Court and then the local authority engaged in pursuing these orders to protect P. The proceedings and orders were successful in protecting P.

As set out above, the lack of understanding of the MCA is evidenced in the assessment of capacity. Generally, the quality of capacity assessments can be very poor across many sectors, including even experts instructed by the Court of Protection, and Court Visitors.

If the Code of Practice set out potentially relevant information to certain types of decision, and set out the guidance given by the courts, the quality of the assessment might improve. There does not seem to be any formal route for the court’s guidance on capacity from its case law to be fed back to practitioners on a regular basis.

Many informal carers will have come across the Act and will be aware of mental capacity assessments being carried out, but without a full understanding of how capacity is assessed or the implications of a finding that someone lacks the capacity to make a particular decision.

Generally speaking, we consider that the right balance has been struck between the protection of the carer and of the individual lacking capacity. We consider that there is scope for more effective communication of the principles of the Act and its consequences for non-professional carers.

Is the Act widely known and understood by those who are directly affected by it and by their non-professional carers? To what extent does the Act provide protection and reassurance for informal carers? Has the right balance between struck between protection of the carer and protection of the individual lacking capacity?

Whilst those who are affected by the Act may have heard of the Act, in our experience it is very uncommon for it to be fully understood by people affected by it as detailed above.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Has the Act ushered in the expected, or any, change in the culture of care?

As set out elsewhere in this submission, levels of awareness of the Act vary from area to area and from profession to profession. There is also a lack of awareness of the Act among the public at large. This means that any change in the culture of care has been limited.

As a provider of legal services for people affected by the MCA, we of course feel confident in our understanding and application of the Act. However, we are concerned that lay deputies do not receive any training on the Act and its implementation and the information they receive from Court is perhaps insufficient to enable the Act to be implemented fully and in the client’s best interests.

From our perspective, individuals in social care and health generally have a good knowledge of the Act and implement it correctly. In the banking arena, we experience serious problems with many banks and individuals not even knowing what a deputy is and insisting on a power of attorney where, in fact, an Order of the Court exists. This in turn makes it very difficult to assist and empower our clients to manage their finances.

In our experience, professionals are often inclined to assess an individual as lacking capacity to make a particular decision where that decision appears to be unwise or is contentious. Professionals often do not provide adequate support to the individual to make a capacitous decision in these circumstances.

Conversely, we have also seen examples of public authorities (usually local authorities) refusing to assess an individual’s capacity at all or concluding that an individual has capacity in the relevant area, in circumstances where there is sufficient evidence to justify a reasonable belief that the individual lacks capacity and where there is a dispute in relation to an issue in the person’s life. This is particularly apparent in cases where there are likely to be costs implications for the public body, either because Court of Protection proceedings are likely to ensue or because there are implications for the individual’s entitlement to social care or health services.

Public authorities are often unaware of the development in the legal tests in relation to capacity and in some cases still address capacity in a global, rather than an issue-specific, sense.

There appears to be a lack of understanding by healthcare professionals of the meaning of ‘serious medical treatment.’ Our impression is that decisions are being taken in relation to medical treatment without proper capacity assessments and consideration of the individual’s best interests, including consultation with family members and where an application to the Court of Protection is required.

Is there any evidence that the provisions of the MCA affect some groups disproportionately? If so, what data exists to compare representation across different socio-economic groups, Black and Minority Ethnic groups, and gender? We have not noticed any particular patterns in relation to the impact of the MCA on different groups in society, and we are not aware of any data which would enable us to investigate this further.

**Decision making**

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Are those directly affected by the Act being enabled and supported to make decisions for themselves to a greater or lesser extent than they would have been in the past? Does the means by which the decision is made – ‘general authority’, Lasting Power of Attorney, deputyship, Court of Protection – affect the quality of decision making?

Generally, those directly affected by the Act are more supported in making their decisions than they were in the past. However, there is much scope for improvement in the way they are supported to make their decisions. There is less focus on supporting people with making decisions than assessing whether they can make those decisions or not.

There are significant differences in practice between decision makers and the quality of decision making also varies considerably. What evidence is there that advance decisions to refuse treatment are being made and followed?

There is limited case law on s.24 MCA.

The case of X Primary Care Trust v XB [2012] EWHC 1390 (Fam); [2012] 127 B.M.L.R. 122 concerned a man suffering motor neurone disease and only able to communicate through communication board, who made a valid advance decision to refuse life prolonging treatment that may have put his life at risk. The court upheld the decision and gave guidance on the appropriate format for making and recording advance decisions. We acted for the family in this case, where at short notice a complex contested hearing in the Court of Protection was arranged to resolve a dispute over the validity of an advance directive.

The case of A Local Authority v E [2012] EWHC 1639 (COP); [2012] 2 F.C.R. 523. Concerned an anorexic woman making an advance decision refusing force feeding, who was held to be lacking in capacity by virtue of her anorexia.

The case of Re M (Adult Patient) (Minimally Conscious State: Withdrawal of Treatment) [2011] EWHC 2443 (Fam); [2012] 1 W.L.R. 1653 confirmed that in the absence of a valid advance decision, the court would carry out a balancing exercise to consider the best interests of a minimally conscious patient, and that had there been a valid advance decision, the court would be bound by that decision. We acted for the family in this case, in a large part on a pro bono basis.

The courts have shown that they are willing to uphold even life threatening advance decisions, and have indicated that these decisions, if valid, will trump the best interests test. The question of whether the decision is valid is fact specific and if required can be examined, but potential problems should be identified and dealt with if possible at the time of the advance decision for clarity.

We provide a service of drafting Advance Decisions for clients and are cognisant of the requirements under the MCA for a valid and applicable Advance Decision. As a firm, we have had relatively few clients approach us to assist with the preparation of an advance decision. We have seen even fewer instances of disputes in relation to advance decisions. It is however difficult to say whether this is because advance decisions are being followed (and so no dispute arises) or because few advance decisions are being made at all. Given the low numbers of clients approaching us to prepare advance decisions, we suspect it is the latter.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
We consider that better promotion/awareness and understanding of Advance Decisions will result in clearer decision making at the end stage of life. Better understanding of Advance Decisions would result in clearer drafted documents that comply with the MCA. This would reduce potential disputes and provide a clearer pathway in health and social care settings with benefits to all parties.

Has the MCA fostered appropriate involvement of carers and families in decision-making?

Families and carers continually seek our advice where public authorities have failed to involve them in decision making. This is particularly apparent during transition, when individuals turn 18 and parents ‘lose’ parental responsibility and are no longer considered to be the lead decision maker in relation to their child’s care. Public authorities often fail to explain the change in legal framework to parents and fail to consider their views as they are required to in accordance with s4 of the MCA.

There is also evidence of public authorities confusing ‘best interests’ decisions under the MCA with administrative decisions. We have experience of cases in which public authorities have correctly assessed an individual as lacking capacity but have failed to properly take into account the person’s wishes and feelings and those of carers and family members, as to do so would require the deployment of significant resources (for example, to put in place a package of care to allow the person to live at home safely).

There appears to be a lack of understanding by public authorities of the circumstances in which they are required to make an application to court and it is submitted that families and public authorities would benefit from greater guidance on this point. Public authorities (particularly local authorities) often consider that they have the ability to be the final ‘decision maker’, even where a family member, or the person to whom the decision relates, disagrees with the public body’s view and the matter should therefore be referred to the Court of Protection.

There is a lack of understanding amongst professionals and public authorities regarding the implications of a family member or carer holding a health and welfare deputyship – i.e., that this entitles the deputy to take the lead in decision making.

Has the role of the Independent Mental Capacity Advocate (IMCA) succeeded in providing a voice for clients and an additional safeguard against abuse and exploitation for those who have no-one to speak on their behalf?

In our experience, IMCAs are in the main very knowledgeable and vocal in defending the rights of those they represent, and in so doing help to safeguard clients against abuse and exploitation. However, the scope of an IMCA’s role would benefit from clearer definition, particularly in relation to their ability to bring matters to the attention of the Court of Protection, either in their own right, or representing the person concerned as their ‘litigation friend’.

It seems clear from the Code of Practice that IMCAs were intended to be able to bring applications to the Court of Protection. However, the appropriate route for doing so is far from clear and, so far as we are aware, there have been surprisingly few instances of IMCAs referring matters to the Court. This is troubling because, by definition, an IMCA will only be
appointed in cases where there is no one else appropriate to represent the interests of the individual P, and where there is a dispute as to what is in the person’s best interests, a local authority or NHS body is extremely unlikely to apply to the Court to challenge its own best interests decision. The Official Solicitor is equally very unlikely to make an application to the Court, partly because the matter would first have to be brought to his attention, but mainly because, for policy reasons, the Official Solicitor only very rarely commences proceedings himself in the Court of Protection. It therefore falls to the IMCA to refer such matters to the Court in the event of a dispute and at present this is simply not happening in anything like the numbers one would expect.

There appear to be two main reasons for the low number of referrals to the Court by IMCAs. The first is the lack of clarity as to the procedure for doing so. The second is the potential for conflict between IMCA organisations on the one hand and local authorities, which have the power to award IMCA contracts, on the other.

Some progress is being made with regard to clarifying the route for IMCAs to bring matters to the attention of the Court. It is now reasonably well established that an IMCA may act as litigation friend for their client in an application to the Court. It has become more common in the past 12 months for IMCAs to act as litigation friend since the Official Solicitor started operating a waiting list for its cases in early 2012, as a result of the pressure on his resources. The IMCA is therefore often the only individual available to act as litigation friend. However, there is still insufficient awareness among IMCAs and other professionals that IMCAs can apply to the Court on behalf of clients, or that Legal Aid is often available. IMCAs also appear to be put off by the, largely unfounded, fear of the risk of an adverse costs order. There is an urgent need for formal and practical guidance for IMCAs about how they can refer matters to the Court of Protection where there is a dispute about an individual’s capacity or best interests. This is crucial to the MCA operating properly and P’s ability to access justice.

Our experience is also that IMCAs may be deterred from referring matters to the Court because of the potential reaction of the local authority/relevant commissioning body which funds the IMCA service and awards/commissions the IMCA contracts. At present, the contract to run an IMCA service in a given area is awarded by the local authority, which also has statutory responsibility for meeting the community care needs of those living in its area. This means that IMCAs may find themselves in dispute with the same local authority and often the same managerial officers of the council that will, a short time later, be making a decision about where to award/commission the next round of IMCA contracts.

Whilst, as stated above, in our experience IMCAs can be fiercely independent and vocal in standing up for the rights of their clients, we are aware through first hand knowledge and anecdotally of cases in which pressure has been exerted on IMCAs by local authorities not to pursue matters and it is clear that at present the system contains the potential for conflicts of interest. A way to resolve this tension would be for the function of awarding/commissioning IMCA contracts to be taken away from local authorities and given instead to the Department of Health or a stand alone body.

Has the level of referrals to IMCAs met expectations? What are the reasons for the regional variations in the number of referrals?
Whilst we are aware that there has been a steady increase in the number of referrals to IMCAs, as we are not involved in frontline health or social care provision, it is difficult for us to comment on whether the number of referrals is appropriate or the reason for any regional variation in numbers.

We can say that we have come across cases where there has been no referral to an IMCA in circumstances where one would have expected a referral to have been made. However, it is not clear if this is as a result of a failure of a local authority or NHS trust to make a referral, or as a result of ‘gatekeeping’ by the IMCA services themselves. We suspect that a combination of both is at play.

Are IMCAs adequately resourced and skilled to assist in supported or substituted decision making for people lacking capacity?

In our experience, although IMCAs do an excellent job, we consider that a lack of resources is preventing IMCAs from devoting more time to individual cases. As awareness of the MCA increases, so does the number of referrals to IMCAs, yet cuts are being made to IMCA services at a time when more IMCAs should be appointed. We are not aware of IMCAs having to turn down referrals, but these cuts may affect their ability to represent clients and the amount of time devoted to individual cases.

The Official Solicitor is also currently hard pressed to represent all potential clients, and the OS currently has currently a waiting list in place. We consider that IMCAs are therefore in a good position to take on the role of litigation friend in cases where the Official Solicitor is not in a position to act. We consider that one of the functions of an IMCA is to bring matters to the attention of the Court of Protection where appropriate and that guidance is needed to set out how IMCAs can do this in order to protect the interests of their clients. There are clear benefits in IMCAs taking on the role of litigation friend in Court proceedings, particularly in terms of the direct contact they have with the client.

We also consider that IMCAs should be independently funded and IMCA contracts independently awarded. This would enable the IMCA to focus on promoting the views and wishes of the person lacking capacity, and would remove any potential conflict the IMCA may experience should they be funded by the same statutory body responsible for the provision of their client’s care.

**Deprivation of Liberty Safeguards**

Are the safeguards in the Deprivation of Liberty Safeguards (DoLS) adequate?

There is no doubt that the scheme is far too complicated if it is hoped to be understood by the general public. As many other commentators have noted, the Schedules attached to the Act and incredibly complex and it is all but impossible for a non-lawyer to read and understand them.

We consider that one of the fundamental problems with DOLS is that there is a misconceived perception that to be deprived of your liberty is automatically a bad thing, when of course for many people it is in their best interests. This can lead to a motivation for someone not to be deemed to be deprived of their liberty.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
The DOLS safeguards are also in our experience viewed by practitioners and family members as being too technical and not practical – something for lawyers to argue about. In our opinion this all stems from a lack of clarity as to what is (and is not) a deprivation of liberty. We hope that the Supreme Court will provide some clarity on that point later this year – certainly the decisions in the Court of Appeal in ‘Cheshire West’ and ‘P&Q’ in our experience have left lawyers and, more importantly, social workers and other staff who are trying to implement the safeguards even more confused about when a restriction becomes a deprivation.

Our experience is that most people implementing the safeguards consider this to be an issue for lawyers only, and that in reality there is little difference. We believe that there is a resource driven element to this – the broader the definition of DOLS, the more cases that are likely to require assessments, forms completed, arise awareness in family members and ultimately come to court.

We have concerns about the protections for those people who fall ‘just the wrong side of the line’ – so are not deemed to be deprived of their liberty but nevertheless have restrictions placed upon them have no safeguards to consider whether this is in the person’s best interests.

Poor understanding of capacity assessments and best interests decision making applies in relation to the DOLS safeguards as much as it does in relation to any other best interests decision.

We have a very serious concern that breaches of the DOLS safeguards are rarely brought before the Court. This means that the individual is left without a remedy, and there is a failure to promote best practice. The reason why these are not brought before the court is that the value of a claim is relatively low – usually less than £10,000 – and so public funding is not available as the cases are often complex and so do not meet the costs/benefit criteria for the Legal Aid Agency to grant legal aid and we have been unable to obtain ‘after the event’ insurance to allow the matter to be pursued under a conditional fee agreement. Even where the case can be brought on legal aid, the Statutory Charge applies and this means that the damages will go back to the Legal Aid Agency, which means that the individual has no motivation or benefit in bringing the claim. It means that the person has been deprived of their liberty unlawfully by a statutory body but they are left without a remedy or access to justice.

At Irwin Mitchell we have seen many cases where there has been a breach of the safeguards, for example where someone is moved to a placement against their wishes but with no authorisations in place. Usually there is some oversight at some point down the line when the matter is brought to court, but at this point it may be too late to move the person, given the (understandable) reluctance to keep moving someone.

We believe that the DOLS safeguards should be extended to include supported living placements, and further clarity is required as to when internal reviews should be conducted. Are the processes for authorisation, review and challenge of DoLS sufficiently clear, accessible and timely?
Our view is that it is essential that there are processes for authorisation, review and challenge of DOLS. Our concern is that they are not currently sufficiently clear, accessible or timely for the following reasons:-

Clear

Our experience is that the capacity assessments that are conducted are often of exceptionally poor quality and fail to reflect the requirements of the MCA 2005 or the case law of the Court of Protection. There does not seem to be any specific training requirement for capacity assessors.

The understanding of the Code of Practice is poor with misinterpretation of it being evidenced in the DOLS paperwork

Further guidance is required about whether DOLS authorisations can authorise the use of physical restraint, and if they can, additional independent oversight and review should be required.

There do not seem to be sufficient internal reviews conducted,

IMCAs are not always involved in reviews.

There is often inadequate information given to Relevant Person’s Representatives or family members about their rights to challenge a DOLS authorisation. For example, they are not generally given a list of solicitors they could contact, or full details of their rights as a Nearest Relative would be under the MHA 1983.

It is not clear whether the Code of Practice is compliant with Article 5(4) ECHR as it suggests that court review of a DOLS authorisation is optional.

There is confusion about the role of IMCAs. They should be focusing on promoting the individual’s views and wishes, not acting as a pseudo-independent best interests assessor.

Accessible

There are problems with appointing RPRs. Often, family members are not appointed if they are already in conflict with the statutory body. On other occasions, a family member will be appointed as RPR who agrees with the DOL, and therefore P’s right to challenge it is not pursued. Where a family member is the RPR, a s.39D IMCA should always be appointed to avoid this problem.

There is a lack of adequate remedies for technical breaches of the DOLS safeguards, which makes it difficult to promote best practice.

Timely

It is very often the case that DOLS authorisations are put in place not at the earliest opportunity and so when P is already in the placement s/he objects to. For example, where P is discharged from hospital to a care home against P’s wishes, but no authorisations are

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applied for at that stage, nor is the Court’s involvement sought. The process to authorise a
DOL in advance is underused.

The Court of Protection and the Office of the Public Guardian
Are the Court of Protection and the Office of the Public Guardian sufficiently understood
and accessible to all? Are they operating effectively and successfully?

We do not consider that they are either sufficiently understood or accessible to
professionals or lay Court users. There is a lack of clarity in the public domain as to the
difference between the role of the Court of Protection and the role of the Public Guardian.

Professionals and clients alike often find it very difficult to reach the Court or OPG by
telephone. Lack of clarity with timescales is also an ongoing problem and this feeds our
clients frustrations as we are then unable to assist them and manage expectations. The
systems that are in place would not appear to be working effectively or successfully and we
often experience files being lost, inappropriately archived, applications being mislaid, typing
errors in orders, incorrect names in orders and applications not being fully dealt with.

Practical issues also arise regarding the Court of Protection being based solely in London,
such as delays experienced in orders being sealed, which poses a considerable problem when
a sealed order is required as a matter of urgency. Serious consideration should be given to
the regionalisation of the Court of Protection, as has been done with the Administrative
Court.

What has been the impact of the introduction of Lasting Powers of Attorney (LPA),
especially with regard to decision making on matters of personal care and welfare?

In our experience there has been very little ‘take up’ for people completing welfare LPAs.
This is no doubt in part due to a lack of knowledge, but in our opinion unless someone has a
degenerative condition and they know that they will lack capacity in the near future, people
do not want to consider issues relating to their welfare.

What concerns, if any, are there regarding the costs associated with registering an LPA, or
with making an application to the Court of Protection?

The costs involved in registering an LPA, and the costs involved in making a Deputyship
application are considered to be unreasonable and disproportionate for many clients. We
find that lay people are largely reluctant to proceed with a Deputyship application or
registering an LPA. This can potentially be extremely serious as lay clients then look to
other means of managing money for someone who does not have the capacity to manage it
themselves and these can include forging signatures and using pin numbers without authority.

In addition, in relation to many small estates (for example damages for abuse of persons who
have been in the care of the local authority) the costs are considered to be wholly
disproportionate, with there frequently being no suitable family member to act and the local
authority being conflicted as being the defendant in any claim. The size of the award for
those claimants who lack capacity does not generally merit a professional deputy and the
charity sector has not stepped in to fill the gap in the way that was hoped.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the
submissions.
Is legal aid available and sufficient? What impact will the recent and proposed reforms to legal aid have?

Legal Aid is available for welfare proceedings in the Court of Protection, but is subject to a means test and will only be granted where the matter requires an oral hearing and concerns one of the following issues:

- The individual’s right to life
- The individual’s liberty or physical safety
- The individual’s medical treatment
- The individual’s capacity to marry, to enter into a civil partnership or to enter into sexual relations
- The individual’s right to family life

Whilst we consider that the current arrangements for legal aid in welfare cases are generally satisfactory, there is one significant area which we believe needs to be addressed urgently in order to avoid significant injustices occurring.

Currently, when the state seeks to remove children aged under 18 from their family home, the parents of those children are awarded non-means-tested legal aid to be represented in the care proceedings. The removal of a child from his or her parents is one of the most significant ways in which the state can interfere with a citizen’s right to a family life and the funding regime for legal aid rightly reflects this.

However, when the state seeks to remove people who are aged 18 or over and who lack capacity from the family home, legal aid for the parents is currently means tested. This means that in very many cases, where the family does not qualify under the means test for legal aid, but is only of modest means and cannot afford to fund representation privately, they are simply not able effectively to put forward their own case in Court. We are aware of serious and significant injustices occurring as a result of this, where in some cases local authorities have simply removed people from the family home without seeking Court authorisation, safe in the knowledge that the family cannot effectively challenge them.

A related issue is that the funding does not expressly cover cases in which an individual’s right to respect for private life under Article 8 is engaged (as opposed to their right to respect for family life – see fifth bullet point above). This means that, for example, if someone is being moved from one community placement to another and objects, he may not be granted public funding, whereas he would do if he was moving from a family placement to a community placement.

Additionally, there are inconsistencies in the way in which the Legal Aid Agency awards funding. We note in particular that the LAA’s tendency to withdraw non-means-tested public funding in DOLS challenges once the court has made any interim declarations about P’s best interests means that DOLS challenges have to be withdrawn due to funding difficulties. We know of cases in which this has happened, which has meant that an individual has not had the independent review of his/her deprivation of liberty required by Article 5(4) ECHR.

Further, since changes to the capital passport for legal aid eligibility in April 2013, it has become much harder and more time consuming to investigate individuals’ entitlement to...
legal aid. This difficulty is compounded if the litigation friend is an advocate or family member rather than the Official Solicitor.

We recognise that there are restrictions in respect of the legal aid fund. In respect of the costs rules - The Court of Protection rules ought to be strengthened in cases of health and welfare. Often families or independent advocates find themselves in a situation where a dispute exists with a social care or medical care state body (local council or NHS body). The state body ought to issue an application to resolve the dispute. Where a state body has failed to bring a dispute, over a legitimate medical treatment dispute or a dispute affecting P's Article 2, 3 or 8 ECHR rights, before the court and another party has brought an application before the court to resolve the said dispute – the presumption should be that the state body bear the costs of bringing such an application. This would enable better access to the public and ultimately proper decision making in line with the MCA. Vulnerable people will not be able to gain access to justice where the costs of seeking legal advice and assistance at a specialist level may be prohibitive or a disincentive to act to settle a decision on what they consider is the best interests of P. Clarity is required to determine the prospects of recovering the costs of bringing such an application.

Finally, legal aid should be available for family members in respect of application to the Court of Protection for ‘end of life’ cases where declarations pursuant to the MCA are sought from the Court. In W v M [2011] EWHC 2443 (Fam) Mr Justice Baker stated:

"260. Thirdly, given the fundamental issues involved in cases involving the withdrawal of ANH, it is alarming to the court that public funding has not been available to members of the family to assist them in prosecuting their application. In the event, the Applicant's team has acted pro bono throughout the hearing and during much of the very extensive preparation. I stress that this has not caused any disadvantage to the Applicant. As I said at the conclusion of Mr. Sachdeva's submissions, the family could not have had better representation. But it is intolerable that the family should have been dependent on the willingness of lawyers to work without remuneration. In this case, the "playing-field" was level because of the exceptional generosity of the Applicant's lawyers. In other cases, members of a family who wished to ask the court to authorise the withdrawal of ANH but did not qualify for means tested public funding may have to appear in person, given the very high costs of litigation. Such a situation would seem to infringe the family's rights under Article 6 of ECHR. There are many demands on the restricted legal aid budget, but consideration should be given to extending the right to non-means tested public funding to family members seeking to bring this type of application. At present, such non-means tested funding is available to parents whose children are the subject of care proceedings under the Children Act 1989. That provision is justified by the fundamental and life-changing consequences which flow from the making of a care order. The same argument applies to applications for the withdrawal of artificial nutrition and hydration"

We represented the family in this case and we respectfully agree with the Mr Justice Baker.

**Regulation**

Is the role of the Care Quality Commission in inspecting on the MCA standards adequate and appropriate? Is there a case for additional powers?
Whilst the CQC collects statistics and prepares reports on DOLS and the MCA, there appears to be no mechanism for implementing any recommendations made by the CQC and no follow up of any anomalies identified in the CQC’s reports in relation to particular local authorities or NHS Trusts.

Additionally, there is no sanction available against public authorities where they fail to comply with the requirements of the MCA, unless the matter is referred to the Court of Protection and there is sufficient merit for the individual to make a claim for damages against the public authority. This happens only in the rarest of cases. It may be appropriate to consider giving the CQC power to apply sanctions where breaches are found.

Should other regulatory bodies, such as health and social care professional regulators, be acting in this area?

As set out above, the commissioning of IMCAs should be via an independent body, and this body should also be actively involved in the regulation of the MCA. Greater clarity on the role of IMCAs would be beneficial, in particular to re-consider broadening the issues for which IMCAs must be appointed, the role of IMCA’s as litigation friends and the funding arrangements to be put in place for this role.

Health professional regulators also need to do far more to require that all clinicians, at every level, undertake mandatory regular training on the MCA, its Code of Practice and on relevant case law. This training should be provided by an independent external agency, and it should also be a requirement that each health body’s contracted legal firm should provide regular updated training/advice on matters.

Similarly, greater awareness of the MCA, Code and the relevant case law and legal principles is needed within the police.

Organisations such as Ofsted and the CQC should offer guidance for service providers and commissioners, particular in situations during the transition period from childhood to adulthood, where there may be disputes regarding best interests in terms of residence for the individual who may be residing within a children’s home, despite becoming an adult, pending resolution by the court.

**Other legislation**

How well is the relationship with the mental health system and legislation understood in practice?

In our experience there remains some confusion as to how the MCA and the Mental Health Act 1983 interact. It would be helpful to have guidance on when the MHA takes precedence, particularly in cases where COP proceedings have already been issued or where the individual has fluctuating capacity or mental health needs. Also, it is unclear what should happen in the event of a disagreement between the Court of Protection and the protected person’s mental health clinician. On a practical level, this tension can arise between a DOLS best interests assessor who refuses to authorise a DOL because in their view the person falls within the ambit of the MHA, and an Approved Mental Health Practitioner who considers that the MHA criteria for detention are not met.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
We have found there to be inconsistency in the knowledge and awareness of mental health professionals in relation to the MCA and the need to authorise deprivations of liberty through the DOLs procedure. There is often a particular lack of clarity in cases where patients have been discharged from detention under the MHA and may need best interests decisions to be made on their behalf. Similarly, there appears to be insufficient knowledge amongst practitioners about the application of the MCA in respect of informal psychiatric patients, and the need to conduct proper capacity assessments in such cases.

**Devolved administrations and international context**

Does the implementation of the Mental Capacity Act differ significantly in Wales?

We have seen relatively few Court of Protection welfare cases originating in Wales and our impression is that medical, legal and social care practitioners in Wales appear to be less familiar with the MCA and the Court of Protection than is the case in England.

What lessons, if any, can be learnt from the approaches taken to mental capacity legislation in Scotland and Northern Ireland, or in other jurisdictions?

Northern Ireland is consulting on whether to extend the mental capacity legislation to the criminal justice system. In our experience, vulnerable people lacking capacity come into contact with the criminal justice system regularly and are not protected by the Act.

The principles of mental capacity legislation in Northern Ireland and Scotland are broadly the same as in England. We do not have any direct experience by which to compare the implementation.

Is the MCA compliant with the United Nations Convention on the Rights of Persons with Disability (CRPD)? Are there lessons that can be learnt from the CRPD for the successful implementation of the MCA?

There are few recorded decisions that consider both CRPD and the MCA. There are areas of CRPD where specific references to rights and obligations raise questions not about the compliance of the MCA, but in the interpretation of the MCA in current law. For example, Article 14 relates to Liberty and security of persons, and states that:

1. [...] persons with disabilities, on an equal basis with others:
   
   (a) enjoy the right to liberty and security of person;

   43 (b) are not deprived of their liberty unlawfully or arbitrarily, and that any deprivation of liberty is in conformity with the law, and that the existence of a disability shall in no case justify a deprivation of liberty.

   Although the restrictions on liberty and safeguards in MCA 2005 amended by MHA 2007 conform with the law, in that it defines deprivation of liberty and introduces safeguards on such situations rendering it compliant with s.43(b) above, there is an obvious tension between this article and the current state of the law following the decision in Cheshire West
and Chester Council v P [2011] EWCA Civ 1257 which has arguably limited the scope of what constitutes a deprivation of liberty.

The DOLS in the MCA 2005 as amended have been held to be compliant with Article 5(1) ECHR (see G v E [2010] EWCA Civ 822), but we are not aware of any judicial findings in relation to the compliance of DOLS with CRPD, presumably because of the unincorporated status of the convention. However, until the state of the law following Cheshire West is addressed, in this aspect of the law at least, MCA 2005 is arguably not compliant with CRPD.

Further, academic comment suggests that the test for capacity itself given in MCA 2005 is not compliant with the pure form of the CRPD. Genevra Richardson states that there is a tension between ‘mental capacity’ in the MCA 2005 and ‘legal capacity’ in the CRPD (Mental capacity in the shadow of suicide: what can the law do? *Int. J.L.C. 87)

She suggests that Article 12 of the Convention, which provides:

(1) ‘States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.’

(2) ‘States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.’

can be read as ‘requiring the law to give the same status and respect to decisions made by people with mental disabilities, however great the impact of those disabilities on their decision-making, as it gives to the decisions made by others. Legal capacity should not be dependent on mental capacity.’ She observes that the MCA as a result may be rendered non-compliant as the MCA differentiates between decisions made with mental capacity and those made without, and imposes substituted decision-making only in relation to the latter. If this argument is to be followed, again the MCA 2005 could be seen as non-compliant with CRPD.

2 September 2013
Our research focus was upon the practical application of the DOLS, through a qualitative analysis from 9 ‘live’ DOLS cases, and quantitatively through an online survey of Best Interests Assessors decision making.

The qualitative arm of the study involved multiple interviews with stakeholders involved in 9 ‘live’ DOLS authorisations.

Interviews were held with the managing authority applicant, the relevant person’s representatives (and/or Paid Representative), the DOLS assessors (BIAs and MHAs), the supervisory body signatory and (where appropriate) the relevant person’s advocate and social worker. The IMCA provider in each of the study sites was also interviewed.

Supplementary data was also gathered from an additional set of care home managers, BIAs, MHAs and SB signatories about individual, anonymised DOLS cases.

In total 52 people were interviewed in the case study phase, and 27 in the supplementary stage of the study.

Data were analysed to explore the impact the DOLS process and authorisation had upon care practice for people subject to the safeguards.

The quantitative element of the study was an online factorial survey of BIAs decision making.

BIAs in 21 local authorities were asked to comment on a series of randomly generated case vignettes BIAs were required to consider whether or not they thought each case would constitute a deprivation of liberty.

In total 798 vignette responses were analysed to identify the factors that were statistically significant in BIAs decision making.

Although in the study we viewed the Deprivation of Liberty Safeguards in their own right, we have also considered how specific elements of the umbrella legislation (the Mental Capacity Act) were understood and/or applied to DOLS practice.

Responses to specific questions

Implementation

6. Is the Act widely known and understood by professionals required to implement it?

How does this differ across different sectors, such as health, social care, banking and others?

We found that Managing authorities (in this study usually care homes) often had to be ‘nudged’ by others (e.g. professionals involved with the person) to make a DOLS application. We suggest that this may indicate a lack of knowledge and/or clarity on the part of some care home staff about when to apply the safeguards.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Decision making

12. Has the MCA fostered appropriate involvement of carers and families in decision making?

We reported that:

- Relatives were generally positive about the contact they had had with the DOLS Best Interests Assessor (BIA) – which was typically face to face, although occasionally over the telephone.
- BIAs used meetings to provide information to relatives about the DOLS process, to seek information about the wishes and feelings of the relevant person and to ask the relatives’ views about what they thought would happen to the person if there were no DOLS put in place.
- Relatives spoke appreciatively of the opportunity given to say what they felt was the best course of action for their family member.

Deprivation of Liberty Safeguards

16. Are the safeguards in the Deprivation of Liberty Safeguards (DoLS) adequate?

- As our study focus was upon the DOLS process, we are not in a strong position to respond to this question.

17. Are the processes for authorisation, review and challenge of DoLS sufficiently clear, accessible and timely?

- Best Interests Assessors were occasionally critical of the short amount of time available to undertake their assessments (7 days in most of the cases in the study).
- Relatives who held the role of DOLS representative were not always clear that they had the power to request reviews of, or challenges to, the DOLS conditions. However, a caveat should be made that in the cases reported relatives were happy with the quality of care and the appropriateness of the restrictions in place.

19 August 2013
In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
JF – Written evidence

I am XXXX XXXX, retired, of XXXX XXXXX.
I have dealt with the Court of Protection over a number of years, in respect of the affairs of my mother. The experience has been very difficult and has had a significant impact on my family and family relationships. I shall limit my evidence to my own personal experience of this Court and its administration, which before this Act was carried out by the Public Guardianship Office.

I apologise for the lateness of my evidence, but I had no knowledge of this Committee until recently contacting the charity “Liberty”, this despite being registered for Ministry of Justice updates.

EXECUTIVE SUMMARY

I. Transparency
Please note Court of Protection Rule 2007

PART 13
HEARINGS

Private hearings
General rule – hearing to be in private
90.—(1) The general rule is that a hearing is to be held in private.
(2) A private hearing is a hearing which only the following persons are entitled to attend—
(a) the parties;
(b) P (whether or not a party);
(c) any person acting in the proceedings as a litigation friend;
(d) any legal representative of a person specified in any of sub-paragraphs (a) to (c);
and
(e) any court officer.
(3) In relation to a private hearing, the court may make an order—
(a) authorising any person, or class of persons, to attend the hearing or a part of it;
or
(b) excluding any person, or class of persons, from attending the hearing or a part of it.

a. The Proceedings in the Court of Protection (COP) are overly secretive. Whilst the need to protect the anonymity of vulnerable persons is accepted, confidentiality can be easily abused, especially when it is applied to persons suffering from a serious mental health problem. Anonymity and privacy are not the same. Justice needs to be seen to be done.
b. In my experience an entire class of persons, grandchildren, who had an interest in the Donor’s Will, were not given notice of an application for a lifetime gift, and despite notice of the Donor’s express wishes, were excluded from the Order.
c. Chancery barristers have repeatedly advised in conference, once even in a skeleton argument supposedly supporting my claim, that despite being a party to all proceedings I had no right to access my mother’s court file, and this in spite of a history of non-disclosure of pivotal evidence.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
d. In 2011 I consulted Senior Human Rights Counsel, Mr [redacted], who advised differently. Consequent to his advice and my solicitor threatening the COP with an action under Article 6 of the Human Rights Act and we were allowed access. However, as predicted, the file had been severely “pruned”.

2. Certainty

Court of Protection Rule 2007

PART 5

GENERAL CASE MANAGEMENT POWERS

The court’s general powers of case management

25.—(1) The list of powers in this rule is in addition to any powers given to the court by any other rule or practice direction or by any other enactment or any powers it may otherwise have.

The court’s general powers of case management

25.—(1) The list of powers in this rule is in addition to any powers given to the court by any other rule or practice direction or by any other enactment or any powers it may otherwise have.

Procedural Rules are there, in part, to ensure proceedings are fair. If any Rule can be dispensed with in “Private” Courts including, in my experience over 12 years, the lack of disclosure, then there is a clear risk of decisions being appealed.

3. Safe Orders for Lifetime Gifts

a. Whilst it may in some circumstances be appropriate for “lifetime gifts” to be made from a mentally incapacitated Donor’s capital, it should not take place until all persons with an interest in the Donor’s Will have been notified and with the benefit of professional independently audited accounts. The Mental Health Act prescribes that the long financial security of the patient is paramount.

b. The Office of the Official Solicitor has been shown to be too close to the COP and therefore not independent. I have been advised by this Office that money gifted to the family is not lost despite clear evidence that most financial abuse of vulnerable adults is from family and carers.

c. A recent Freedom of Information application has confirmed that there is no requirement for an independent audit despite the prior history of my having to appeal a gift admitted at the time by the Official Solicitor’s office as being “unsafe”.

4. Applications and Appeals

a. Hearings should not be heard by Judges who have made previous judgments/decisions which are known to be unsafe or have raised concerns. I have experienced this in both the COP and in a related application in the Chancery Division.

b. A Judicial Decision/Judgment that an application “is not in the interest of the person lacking capacity should not be accepted as a reason for an application or appeal to not be heard unless there is a reasoned written explanation.

c. Appeal costs should not be put against the incapacitated Donor where one of the parties was clearly at fault for the previous decisions; this includes representatives from the Official Solicitor’s Office who failed to represent their incapacitated client.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
I had an application dated 10 June 2002, exhibiting independent evidence of financial abuse, some following an Order of the COP, refused a hearing, and an appeal against a Decision of the COP refusing me access to my mother’s file, dated 11 September 2007, but not forwarded until a month later after the new Rules came into force. Again this was never heard. The Chancery Listing Office confirmed that the COP had requested a hearing date for the appeal and then had it removed. I had notice of either event and all efforts to have them heard failed. Both times it was argued by the COP that they were not in my mother’s interests.

5. Solicitors should have a duty to preserve files where there is knowledge that they might be subject to a later Order for Disclosure.

This is particularly necessary in contentious matters concerning a person who lacked capacity and there is a clear probability that there will be further legal proceedings following that person’s death. The Law Society imposes no such obligation.

6. Witnesses, parties and legal professionals should be held to account for false statements in matters concerning persons lacking mental capacity as these vulnerable people are not able to protect themselves from deceit.

a. The COP is served by specialist Chancery Barristers, who form a close community with members of the Official Solicitor’s Office and COP administrators. In my experience this is not always in the interests of the person lacking capacity.
b. Primary source evidence is not sought, or even when available often ignored; exhibits are not examined as to whether they support witness statements or skeleton arguments. Decisions seem to be made entirely on the basis of skeleton arguments and oral evidence from Counsel. Counsels have a carte blanch excuse for statements proved false by blaming their clients. Apparently they are under no duty to ensure that their arguments are accurate even where there is primary source rebuttal evidence.
c. I believe this is the result of closed courts where a select group of practitioners know they are not under scrutiny.
d. There should be an extra burden on the COP to ensure that Decisions are based on facts and pivotal evidence as the subject of the matter is not able to give reliable evidence to protect their welfare and wishes. The COP should be under a strict duty to ensure that all necessary enquiries have been made and that all relevant evidence disclosed to all parties.
e. Instead we have the opposite scenario: Closed courts where all procedures can legally be ignored.

SHORT HISTORY

a. My father died in April 1998 naming his three daughters as executors and trustees. He made my mother the sole life tenant of his will trust, with the residual estate being equally distributed between his daughters, or if any predecease my mother, to their respective children. Only two daughters extracted probate; however as the youngest I had less rights as all correspondence was directed to my older sister as listed on the Grant.
b. In November 1998 my mother and co-executrix signed a deed advancing considerable capital from my father’s will trust. The same person witnessed both signatures. Despite having no notice of any plan to advance money from the trust, my sister expected me to sign the deed and for it to be executed with immediate effect. I refused in the sure knowledge that my mother did not have mental capacity.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
to understand her financial situation, which was limited due to private nursing home fees and uncertain as she was mainly reliant on rental income from two high street shops.

c. To protect my mother I asked her General Practitioner to examine her as to her mental capacity. This examination took place in the Home on 30 November 1998. The Doctor found my mother to lack capacity and I consequently, as was my duty as one of her attorneys, applied to have her Enduring Power of Attorney registered.

d. My co-attorneys, my sisters, objected, claiming inter alia, that my mother had not yet lost mental capacity.

e. Registration failed on a technicality due to the solicitor’s poor drafting and I was advised by the Public Guardianship Office (PGO), then the administrative branch of the COP, to apply for Receivership. I followed this advice forwarding the name of two suitable solicitors; however without my knowledge my sisters had instructed a new solicitor to register an earlier limited EPA which only named them as attorneys.

f. On 05 January my co-executor took my mother to the new solicitor and had a codicil drawn up removing me as her executor. The solicitor’s attendance note shows that my mother believed me to be a trouble maker making difficulties about the administration of my father’s estate. She clearly did not understand that I was causing my sisters trouble, not her, and was in fact protecting her by not signing the deed and applying to register her EPA thereby supposedly preventing her making any further unsuitable gifts.

g. My mother’s will and codicil were not disclosed in the hearing at first instance or the appeal (Re: E February 2000 Mrs Justice Arden), but only reluctantly by opposing counsel during the hearing of my sisters application for a lifetime gift in August 2000. The will confirmed my argument that the grandchildren had an interest and should have been given notice. My daughter had been refused an application to be joined as a party. No independently audited accounts were before the COP. The representative of the Official Solicitor who was acting for my mother had not requested sight of the will nor my mother’s past tax returns. After the order he admitted that the Gift was unsafe, but said that it was due to the Court being unaware of the costs of the on-going appeal to the Court of Appeal. However an Order was made ignoring the grandchildren. I appealed.

h. The Appeal to the Court of Appeal was due in part to my attending the offices of the solicitors who drew up both my parents’ last wills and EPAs and obtaining copies of the files. In the EPA file was a letter from the solicitor to my eldest sister saying that it was just as well we had “replaced” the earlier Power.

i. At the time of the Gift hearing we had an order from Lord Justice Aldous that a hearing for permission to appeal should be expedited, with a window for the appeal, and that it should be heard by at least 2 Lord Justices.

j. My solicitors later obtained a witness statement from the solicitor who drew up the later Power which contradicted the claims made by my sisters and the evidence relied upon by Lady Justice Arden and the hearing at first instance.

k. I was advised by counsel on costs grounds to settle the appeal on the basis that my sisters should produce accounts from the time they started acting as attorneys and if I found evidence of financial irregularities, to make a new application to the COP. I followed his advice, had the necessary evidence from an independent Chartered Accountant, made an application to the COP on 10 June 2002, but it was not never heard.
m. On the basis of the financial documentation disclosed as a result of the appeal to the Court of Appeal, a safe gift was made which protected the grandchildren’s interests.

n. Despite this evidence and the misrepresentation by opposing counsel of the previous history, of which he had personal knowledge, I was removed as the result of a Part 8 application by my sisters, as executor for my father.

o. In 2005 I made a complaint to the PHSO about the conduct of the PGO. My complaint was rejected without the PGO having to disclose any supporting evidence. When later attending a meeting in the PHSO offices with other users of the PHSO, I learnt that in all their complaints, the public bodies in question had been required to supply supporting documentation.

p. In 2007 I made a Freedom of Information Request to the PGO for copies of the documents relied upon by the PGO in its defence to my complaint.

q. On 11 September 2007, at a hearing in the COP, I appealed against the refusal to disclose the documents or access the file. The Decision dated the day of the hearing was not forwarded until 08 October. I appealed, but again it was never heard.

r. Following advice from Mr XXXX XXXXX, my solicitor and I were allowed access to the file which had been severely pruned. My solicitor could find no evidence to support the PGOs defence to my complaint to the PHSO.

s. Having the new evidence from Mr XXXX and my solicitor I requested the PHSO reopen my complaint. The PHSO refused. I could not afford a Judicial Review.

t. It is apparent that the false histories of these proceedings, relied upon in later Decisions, have been used to characterise me as a vexatious litigator and trouble maker and therefore that I have no credibility. I have supposedly been acting purely out of malice against my sisters. At no point has any witness been cross examined or all relevant documents disclosed.

u. At the time the deed advancing capital and the codicil were executed, I was working at Boodle Hatfield Solicitors in Oxford administering estates and trusts. I have legal and business qualifications and had administered the estate of a family friend, the estate forming a large part of my mother’s free capital. I have experience of County, Family and High Courts and of Employment Tribunals. I reasonably expected the COP to act in a similar manner. I have been repeatedly shocked by the conduct of the COP, and it is clear from High Court Judges that they expect the v. Lower Court to have acted properly and dismiss the possibility of any irregularity.

v. What I find even more concerning is that only two of the four Chancery barristers acting for me were prepared to criticize proceedings in the COP. One, after being appointed to sit on the Lord Chancellor’s Committee reviewing the Enduring Power of Attorney Act in 2002, changed. The other Counsel, before a High Court in 2011, was received with a degree of incredibility when she corrected past inaccuracies, and detailed previously ignored facts e.g. the Order of Lord Justice Aldous.

**PREVIOUS CONSULTATIONS**

Until this Select Committee, to my knowledge, there have been two former committees reviewing or advising on the present Legislation and Rules: The Lord Chancellor’s Committee (2002?) and the Committee to Review the COP Rules (2007). The members have for the most part consisted of the narrow field of specialists in the court, the inner circle. I contributed to the public consultations about the Mental Capacity Act and the new COP Rules and detailed my concerns about lack of procedure and private courts. I understand that the consensus of the Lord Chancellor’s Committee was that the court

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should stay “informal”. My evidence was forwarded by the Head of the Family Division to the later committee.

30 August 2013
JF – Supplementary written evidence

I would be grateful if the Committee would allow me to add more evidence to my submission dated 30 August last.

Following the PHSO accepting an unsupported defence from the Public Guardianship Office I requested sight of the relevant documentation and was refused being told that it was exempt under s.32 FOI Act, now being part of the Court File. I therefore made an application to the court for access, my having been a party to all proceedings, but at a hearing on 11 September 2007, was refused.

My solicitor recently suggested I make a claim for the return of the £400.00 fee I paid to appeal this Decision, which was never heard. I had made numerous attempts to recover this fee and had been repeatedly refused. The Decision was dated 11 September 2007 and yet it was not forwarded for a month, despite my chasing. It also took a considerable time to obtain the recording so that I could have a transcript of the hearing. I discovered later that I had been advised wrongly by the CoP as to where to lodge my appeal, i.e. with them instead of the Chancery Listings Office. I also learnt much later from the Chancery Listings office that it had been listed and then withdrawn, both without notice to myself.

We have not received a Defence to my claim despite the request for an extension of time and therefore our claim for a Default Judgment is presently with the Central London County Court.

Secondly, due to my wrongly being denied access to the CoP file I contacted the Information Commissioner’s Office. The complaint was dealt with by a senior caseworker, Mr XXXXXXXX. The PGO/CoP went to great lengths to stop me having access and their argument was upheld. however, Mr XXXXXXXX was not happy about the situation and agreed to keep the file open.

When, on the advice of Senior Human Rights Counsel, we threatened the CoP with an action under Article 6, my solicitor and I attended the CoP on 2 occasions and he made a witness statement to the effect that the PGO’s defence made to the PHSO could not be substantiated by the file. The PHSO however refused to reopen the Complaint despite this new evidence from an Officer of the Court., stating that the file had been destroyed. Consequently I made a FOI application for the names of the persons in the now Office of the Public Guardian, who were responsible for the false Defence. Surely a matter of Public Interest as these individuals could be charged with Misconduct in a Public Office.

On receipt of an unsatisfactory reply from the Ministry of Justice, I requested a Review. This has not materialised despite being way out of time. Consequently Mr XXXXXXXX has recovered the file and is taking the matter further.

Regards

[Redacted]

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
(1) The two major problems with the functioning of the Court of Protection are the secrecy it maintains and the draconian powers it wields. The powers the Mental Capacity Act 2005 vests in COP allow relatives and family members to be kept totally in the dark about the fate of a family member who has become a ward of court. A decision once made by the court dictates the future of the ward without any real possibility for altering that status. And all this happens under the pretext of "protecting the ward".

(2) Although this is not obviously always the case, I can only go from my own experience in dealing with the COP. It serves as a case in point, and I should imagine is in no way unique.

(3) After a divorce my sister had a fall in her home in 2002. Consequently she suffered brain damage and was declared a ward of court with a court-appointed deputy. I was notified of my sister's situation in the spring of 2012 in conjunction with a statutory will application by her deputy. The COP had ruled long before this that I am not to be given my sister's address or to know who her deputy is.

(4) To my horror I suddenly find out in 2012 that my sister is in care and has a traumatic brain disorder due to a coma lasting 3 days. According to the statutory will application my sister alleged that I physically and sexually abused her many years ago and that she does not want to have contact with me.

(5) Living in Finland with my wife I did not contact my sister for several years, because I have been undergoing therapy myself to piece my life together after childhood memories that have surfaced pointing to the fact that both my elder sister and I were sexually abused as children by our father. This process has been very painful and time-consuming, and I didn't want to burden my sister with it.

(6) Since finding out about my sister's accident I have been trying to get an order from the COP to grant her one visit a week by a person trained in the rehabilitation of brain injured victims. I even signed a voluntary affidavit that I will not try to contact her or find out her whereabouts. According to her deputy, she has never had visitors. Her psychologist visits her once a year.

(7) My application for permission was on the judge's table in February 2013. Since then I have contacted the court by letter and phone calls to find out what is happening, to no avail until 26 August, when I received an order refusing permission made on 26 February 2013, but served on 20 August 2013! The order refusing permission without a hearing contained no reasons whatsoever for the refusal.

(8) This would seem to be contrary to the COP rules 2007 PART 2 5(2) (k). But then according to rule 28 "an error of procedure or failure to comply with a rule does not invalidate an order". My point is that an individual is at the mercy of the court's decisions. I have to live, for the rest of my life, it seems, with the anxiety of not knowing how my sister is doing, what her state of health is or what her living arrangements are. And this is because of something my sister said in a mixed-up and delusional state after a coma ("brief psychotic episodes" to quote her consultant psychiatrist and responsible clinician).

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(9) Was it the Lords' intention to mandate the patient's isolation by passing the Mental Capacity Act 2005? Can failure to give reasons for an order amount to denial of justice? Surely giving reasons helps good administration. To establish a right to reasons without this loophole of rule 28 is an essential part of a sound judicial system. By not giving reasons the judge renders, by his silence, it virtually impossible for courts to perform their appellate function, or to exercise the power of judicial review in adjudging the validity of the decision. Reasons substitute subjectivity by objectivity.

(10) In my opinion delaying the issuing of an order that was made 6 months prior prejudices the legal standing my sister and I are in. Again, no reasons were given.

This evidence is submitted on an individual basis.

1 September 2013
In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
I wish to submit the following information for consideration, on an individual basis, and in regards to:

**Committee on the Mental Capacity Act 2005**

One of the five statutory principles of the mental incapacity act:

**‘Best interest’ decision-making**

1. Our personal experience of this particular principle is that while alleging that decisions are being made in our son’s ‘best interest,’ decisions are primarily made in the support workers/professionals best interest instead, e.g. promoting the use of excessive snacks to ‘problem-solve’ to minimise/distract from violent behaviours. This has occurred despite our 25-year old son being several stones overweight; despite his history where he is known to eat until he vomits and despite the strong link to type 2 diabetes in the family, i.e. his father has the condition, all 4 of his father’s brothers have the condition, as does 1 of his 5 sisters. Moreover, our son has been assessed as pre-verbal age-1 ability and does not understand the negative impact that eating to excess will have.

2. Furthermore, we have found that our son is only permitted to make the few decisions that he is able to make for himself – and in which will cause no harm to him – if the Team agrees with the decision, e.g. if he is suffering from sensory-overload and finds holding a spoon difficult/painful, the previous clinical psychologist believed that he should still be made to feed himself as he is able to do so some of the time. This is not only taking one of the few choices that he can make away, but it is cruel.

3. There were also previous issues where our son was placed on a restrictive diet at day services simply because he is unable to load his spoon when foods have less substance, e.g. yogurts, jellies, spaghetti, etc; again, we do not believe that it is fair that our son should not experience and enjoy certain foods simply because he requires more assistance when eating them. He is being punished for his lack of ability and his choices are being restricted – not in his best interest, but again, because it was easier for the support workers to manage.

4. But the most worrying part is that if families speak up for their loved-ones, as we have always done, they risk the threat of having child/adult protections orders being issued against them without cause, as has happened in our case.
5. We immediately submitted a complaint when a referral was made by a professional within the local health board against us. A PoVA referral was made via email and before either we, or the support workers who care for our son daily, were interviewed or given a chance to defend ourselves.

6. The stage 2 complaint findings corrected most, but not all of the allegations and so we progressed our complaint the local government ombudsman. It has now been proven to be a dubious referral but some unscrupulous professionals/organisations are threatening the use of these child/adult protection referrals as a tool to aid compliance (please scroll down to a print-screen of an email which was sent via the network last week by another lady) and once they have been issued, the label will always be in place - even in our own situation.

7. This is an appalling situation and one we have raised awareness of with the ombudsman and our own AM Ms Lynne Neagle.

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15 July 2013

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
The Judith Trust – Written evidence

The Judith Trust seeks to promote greater social inclusion and understanding of people with a learning disability who suffer mental ill-health and therefore the Mental Capacity Act is of particular importance to us. Please note that Dr Annette Lawson, who is the Chair of the Trust, will be happy to give oral evidence to the Committee with her sister Judith Le Vay Lawrence, currently a Ward of Court due to her life-long learning disabilities and mental illness.

1. Overview and context

The Judith Trust supports the objective and principles upon which the MCA is based - to ensure vulnerable people who are permanently or temporarily unable to give rational and informed consent have their human rights protected and to seek to ensure minimal intervention and prevention of the exercise of those rights. However, there is a disconnect between theory and practice. The current Code of Practice (as set out by Lord Falconer) is lengthy and difficult to relate to in particular contexts. The key points of the Act need to be broken down into easily accessible documents or appendices suitable for different groups of professionals which explain how to apply it in practice along with case studies as examples.

2. Implementation

Rather than provide a clear and easy way to protect the rights of service users anecdotal evidence suggests that the MCA has often proved very difficult to interpret and, worse, difficult to interpret in practice. Unfortunately, the MCA, its principles and main objectives have also not filtered through to the people for whom it was designed to help. The Code of Practice contains much that is useful but those that know about it (not many seem to) find its density inaccessible and hard to understand.

In the absence of any clear guidance professionals, in particular, have taken a cautious, self-protective approach and have interpreted the Act from that perspective. For example, there is a tendency to apply a blanket approach regardless of the circumstances in order not to flout what are perceived as service users’ human rights.

The Act and Code of Practice clearly state that judgement should be used and applied to the specific situation at hand, especially relevant for service users whose capacity may change depending on the nature of their medical condition, the type of decision they need to make, and the context of that decision.

The lack of confidence experienced by many carers means that this kind of judgement is not being made, which is clearly not in the best interests of the user.

One example is provided by a learning disabled and schizophrenic lady of 74 who wants to go shopping all the time – she will buy things she does not ‘need’ and cannot find room for and repeatedly buys the same objects – not one watch or clock but 5 or six, for example. Already with a DVD and a TV that plays DVDs, she buys another because ‘it looks nice’ but is so big she cannot fit it on any surface in her room. The family argued that she flourished within clear and supportive boundaries with carers she trusted and with whom she had a

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good relationship. She needed help to make decisions about what to buy and when and how many and so forth. But the professionals, because they considered she could make such decisions and give informed consent in these matters, decided they had to provide someone to go shopping with her whenever she wanted (she cannot manage alone) and to let her spend her money on whatever she wanted. The context of this particular problem is also that this lady has special difficulties in terms of intellectual capacity with number and value – she cannot conceive of bankruptcy; of the difference between £5, £35, £105 or £500. But will say, ‘don’t you know I am rich? I’ve got thousands of pounds’. The professionals felt that not to provide such daily ‘care’ might be a case of deprivation of liberty. This was especially so since the Act specifically mentions the right to make unwise decisions, as we all outside the remit of the Act, may. The institution involved (a residential home) invited their local social services to consider a DOL against the wishes of her family, which fortunately they rejected. It seems unlikely the professionals had studied the Code of Practice which makes a number of recommendations that readily be applied.

The Trust considers that there should be much more understanding of the diversity of needs which exists among service users, and room created for a more practical approach to be applied. While the Trust subscribes to the principle that due regard has to be paid to the rights of the individual, we also think it is important that those rights are upheld within a context of co-existence with others. There is a problem in a rights-based argument where the individual is not seen as in relationship to and with others such as family, carers, community and strangers. Their behaviour impacts others and may cause distress. It may inhibit expression of another’s individual right and lead in the longer term to greater paucity, not richness of life.

3. Decision making

Anecdotal evidence highlights that the MCA has been less than successful in fostering the involvement of carers and families in decision making and clearly that needs to change. The uneven nature of access to Independent Mental Capacity Advocates (IMCAs) is also problematic with community practitioners suggesting that IMCAs, along with non-statutory advocacy generally, are being financially squeezed. This obviously has serious ramifications for the most vulnerable service users and the ability to access what the MCA states is their human right. The process of how and why Commissioners, i.e local authorities, make decisions, needs to be available for public scrutiny.

4. Deprivation of Liberty Safeguards

DOLS needs to be more transparent and could perhaps follow the process of Mental Health Tribunals which seem more relevant, i.e. automatic access for review of decisions.

5. Regulation

Monitoring clearly needs to be improved, especially regarding access to IMCAs. However, the key will be creating a cultural change where the needs of the service user is paramount rather than the production of yet more hefty manuals. The Care Quality Commission (CQC) already monitors and reviews the use of the Deprivation of Liberty Safeguards (part of the MCA) and the Mental Health Act. Ensuring parity of powers so that the CQC also monitors the use of the MCA would be an important step towards ensuring the MCA is correctly implemented and applied in practice.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
6. Other legislation

There needs to be more clarity regarding the distinctions between the MCA and the Mental Health Act, particularly in light of the review of the Code of Practice for the latter next year. The Judith Trust is more likely to deal with people who are affected by the MCA, however more general feedback points to the blurring of the lines between the two Acts, particularly when care staff or other professionals are not entirely sure of how they differ. Treating someone with a mental illness under the MCA could be inappropriate even if they have been detained under the Mental Health Act as lack of capacity applies only “when they experience a mental health problem that affects their ability to make a particular decision” Mind Legal Unit 2012

2 September 2013
KA – Written evidence

Dear Madam

Re: [redacted] 1921-2006 Patient of the Court 1979-1986

I have been struggling for decades to help my father, and since his death in 2006, to protect my family and hopefully others from the difficulties caused by the continuing culture of secrecy and confusion in these two institutions, the Court of Protection and Office of the Public Guardian. Unfortunately in my long experience the continuing culture of both institutions is still, post the Act, not that of a modern democratic institution, although some individuals within the structures do their best to help.

It is admitted now

1. The files in my father’s case were mistakenly said to have been ‘lost or destroyed’ for decades.

2. No references were taken up in 1984 on a carer appointed on my father’s behalf. The family of his previous deceased employer described the carer as a fraudster and thief in writing to me.

This man admitted ‘kicking (my father) up the bum’. This was said to be a cure for alcoholism. It seems likely my father was physically abused by the publican he was oddly allowed to live with before the appointment of the carer. A forgery of my father’s signature has been found on a building society account opening form.

3. My father’s private mail was intercepted by the Court for at least 5 years, until his discharge in 1986 into the sole care of the appointee. My letter thanking him for his birthday card to my eldest son did not reach him. He did not receive my letters telling him of the birth of his second and third grandchildren.

Even when we wrote to ask why we no longer had replies to letters to our father this was not looked into and our letter was ignored.

These are things with a long history and I only summarise them. There are also many other deeply disturbing points revealed in the files, which I was not allowed to see until 2009.

Continuing confusion over judicial decisions

One crucial and continuing confusion is whether decisions were Judicial decisions or not.

It is still unclear whether the failure to take up references was a judicial decision or not. Having been told several times in writing by the Court that it was a judicial decision that assertion has recently been reversed. The Minister Helen Grant has also been misled over this and I am currently trying to get agreement by the OPG and the Court as to the decision process involved in these upsetting actions taken in my father’s care. I have found myself repeatedly fobbed off over the years, with judicial decision the first line of avoidance of engagement by the Court. Finding that was wrong is a surprise. As a result of this confusion my access to the complaints procedures has been delayed over and over again, so the other claim readily rolled out is that these things happened too long ago to be investigated.

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
I believe a proper user group accessible to all users of the Court and OPG could help solve these difficulties. The Court of Protection has what it calls a user group which is in fact a professional’s consultation group, accessible only by people agreed by the Senior Judge. I am very glad this is being looked into and if I could help by elaborating any of the above I would be happy to do so.

2 September 2013
The Act aims to protect the rights of people whose mental capacity is in doubt, and people without mental capacity, and clear up confusion about who is entitled to make decisions on their behalf.

When answering the Questions it might be helpful to think about your own caring situation and the needs of the person with dementia you care(d) for.

On a day to day level, family carers have frequently been in a very difficult position when it is necessary to make a decision for the person they care for and mental capacity may be an issue. In our experience many families don't understand the Act and how it can be used constructively. There can often be a conflict between the needs of the family carer and those of the person with dementia.

My husband lived with Alzheimer’s for 18 years; the last two years in care homes. He received Continuing Health Care for four years, following an accident and a month in hospital, but this funding was withdrawn in spite of several Appeals, for the last two years of his life. I took his case to a retrospective Appeal after he died in May 2012, at which time we won back his funding for the last year.

It would be helpful if when answering any of the questions, if you could include examples of any relevant concerns or issues you have that are relevant to mental capacity.

Questions to be considered in relation to the Mental Capacity Act 2005 (MCA 2005):

Implementation

- Have you ever received any explanation or guidance on the Mental Capacity Act 2005?

Yes, but only when I researched it for Appeals.

- Is there a satisfactory balance between enablement and protection (especially in relation to dementia)?

Now that community Psychiatric Nurses have been more or less phased out, family carers are left to find out what they can, and are mostly too distracted and exhausted to wade through the paperwork. I did my research in readiness for Appeals, and with help of advocates. This would NOT have been possible on my own. There is much too much jargon around these questions

- Is the Act widely known and understood by professionals required to implement it?

No. Care Home Managers and staff need training and monitoring. Home care companies and staff, and Social Services staff all need detailed training.
Has the right balance between protection of the carer and protection of the individual lacking capacity?

In our experience, no; My husband's needs were often sacrificed for the convenience and timetable of care workers, and exaggerated health and safety restrictions, both at home with visiting carers helping me, and in the care homes where he spent his last two years. In a Decision Support Tool for NHS Continuing Health Care, his 'Emotional and Psychological needs' were scored as non-existing!

Our experience was that the NHSS's aim was to show that he had a low score, in order to withdraw his funding. A person in their 18th year of Alzheimer's clearly has extreme health needs, but I had to work VERY hard with expert help, to win back his funding retrospectively at Appeal.

Has the Act ushered in the expected, or any, change in the culture of care?

It has made a difference, when family carers are supported in its use, and helped to bring it into consideration of a loved one's needs

决策

决定

What evidence is there that advance decisions to refuse treatment are being made and followed?

My husband's wish to not be resuscitated when it was clear that he was at the end of his life, seemed to have been followed, but I was very upset that I was away for a week just before the last days of his life and his end seemed to have been manipulated by the care home staff. I have asked for their records, but so far have not received them.

剥夺自由所依据的保护

Are the safeguards in the Deprivation of Liberty Safeguards (DoLS) adequate?

No. When my husband was in his first care home, I spoke to the Manager and members of staff a number of times to point out inadequacies in his care. After 18 months he was evicted on the grounds of my 'whistle blowing'. I contacted the Safeguarding Team on the grounds that his health would suffer if he was moved; they would not intervene, and his health did suffer.

The Court of Protection and the Office of the Public Guardian

What has been the impact of the introduction of Lasting Powers of Attorney (LPA), especially with regard to decision making on matters of personal care and welfare?

I am in the middle of completing my LPA - we shall see what the impact is; at least it urges me to think about my assets, and my possible care needs, in the light of 18 years as a carer.

27 August 2013

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Overview and context

1. **To what extent has the Mental Capacity Act 2005 (MCA) achieved its aims?**

It has raised awareness and challenged clinicians’ thinking about the rights of those who lack capacity. However, many clinicians still find it difficult to let go of their paternalistic ways, which they were and still are, trained with. Learning the Act is easy but applying it to clinical care is a struggle, especially when you have been taught along the medical model.

The implementation of MCA has largely focused on protection than enablement, and a review of the legislation should promote and put more emphasis on the enablement and human rights element of care and treatment. Practitioners tend to ‘bring in’ MCA when a vulnerable service user is determined to be lacking in capacity and the rest of the statutory process followed.

The MCA is a long way from achieving its aim at this time. This is from evidence of carrying out audits of safeguarding cases.

The offences in the Act appear to need some greater clarification as even when serious concerns arise the police prefer to use legislation other than MCA as the evidence of wilfulness is difficult to prove, also the level of mental capacity at the time the offence was committed is often difficult to prove in court. Police use common assault or fraud where they can.

The MCA is undoubtedly a piece of adult safeguarding legislation and one which empowers people to make decisions in their best interests, but it does not appear to be considered in practice for people who have capacity. It seems all too easy to determine that someone is lacking capacity when information could be explained in a way which enables the person to make a decision if the right steps to aid communication were taken.

2. **Which areas of the Act, if any, require amendment; and how? At the core of the MCA are its principles and definitions of capacity and best interests. Are these appropriate?**

The Term Best Interests is not helpful. All doctors and nurses believe they already work in the patient's best interests and do struggle to see what is really meant by its implementation.

The principles and definitions are appropriate but there are significant challenges especially lack of understanding about the person being able to make unwise decisions. In complex Safeguarding cases there are often a wide range of issues that are interrelated and where mental capacity is central to all of these. The different opinions of social workers, nurses and psychiatrists and psychologists can obscure the abuse issues and make it difficult to resolve concerns.

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The two stage test of capacity (Ss2 & 3 of the Act) requires greater clarification in relation to how capacity is assessed, this can be clarified within the Code of Practice. Mini mental state examinations are not a wholly adequate way to do these. The 'spirit of the MCA' must be considered in all practice, particularly amongst GPs and hospital doctors. We still see 'lacks capacity' written in notes without any consideration of the decision and how capacity was maximised and what evidence is present to reinforce this determination. When the MCA code of practice first came out it would have been useful to have had a template for record of assessing capacity. Not sure if a mandatory document would help at this late stage for the organisations that have already implemented their own but would certainly help those that have not.

One way forward is to have a national suggested template which if existing forms cover the same areas could co-exist.

3. To what extent have the five principles of the MCA been implemented in frontline practice? What evidence is available to assess this? Is there a satisfactory balance between enablement and protection?

Assuming someone has capacity is sometimes used to avoid the process. Allowing people to make unwise decisions makes clinicians feel very uncomfortable when they know that the patient will be returning to hospital soon probably in a worse state because of that unwise decision. The balance is controversial.

What is less clear is how much the 5 principles of MCA are an integral part of all social and health care, relating to all service users including those with capacity. The principle of supporting decision making, maximising/helping to develop/improve someone's capacity and involving them in the decision making process, is not given enough consideration.

There has been a vast amount of excellent training for MCA but this has not necessarily lead to it becoming embedded in day to day practice and resulted in recorded MCA assessments. There is a lack of understanding about the need to record when a person has capacity what their views and wishes might be. The MCA intends to empower vulnerable adults and in some cases it does but families do not understand it and are very challenging in some cases when they want the person protected from everything which is not in the person best interests. The offences need to be looked at again so that it is clearer what the offences are and what has to be proven.

1. Presume a person has capacity.

This can be misleading. Assumption of capacity is a bit of a judgement unless common law issue of consent is addressed and the two should not be separated. In order for consent to be valid we have to give information of risks and benefits and make sure it is understood. From a health perspective you can only assume capacity once you've gained informed consent.

2. Support decision making

Needs to say ‘support decision-making whether person has capacity or not’. Information/support should be given whether person lacks capacity or not – or an on-going
Kent and Medway MCA Local Implementation Network – Written evidence

obligation and therefore becomes difficult for front-line staff to implement. Support is usually information giving rather than enabling. People are risk adverse.

3. Unwise decisions

Real concern over unwise decisions and self neglect and thresholds and on-going unwise decisions are apparent. People using it as an excuse for not acting – where does acting in someone’s best interests arise with risks within unwise decision-making? Processes and safeguards do not appear to be in place for self-neglect.

4. Best Interest

Problem with terminology - a different meaning evolved – needs to be clearer: in law can only use that term once you’ve determined someone lacks capacity.

In health there is a problem with the medical profession’s paternalistic approach – they think they always act in people’s best interests, for example, ‘Everything I do is in someone’s best interests.’

5. Least restrictive principle.

Not sure general health professional knows what this means. Mental health and LD services are much more readily aware and application is better. This requires a change in people’s thought processes especially in general nursing.

4. How effective was the Government’s implementation plan? What measures were taken to ensure that professionals and families of those who lack capacity know about and act in accordance with the provisions of the MCA? Has it led to sustainable change?

The implementation plan was poor. This is undoubtedly the most important piece of health and social care legislation to hit the statute books in years and it’s a piece of law which has the person at the centre of its principles. Why was this not celebrated as such? When training is given to families (six years on) they are amazed this piece of law is in force and are comforted that it does actually serve to protect their loved ones who may lack capacity. Family members are amazed that ‘powers’ they thought they had by virtue of being a family member do not actually exist. Why has this information never been circulated to the wider public?

Consulting others is done poorly. Clinical staff often shy away from conversations with family and IMCAs. The public do not know about the Act.

There is still a long way to go to embed MCA into the practice of professionals, including GPs and consultants as well as social workers and nurses. It has a very long way to go for members of the public and families.

Knowledge by informal carers is very limited unless they have had direct contact with professionals who have successfully explained what the aspects of the Act means in practice.

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5. **Is the Act widely known and understood by professionals required to implement it? How does this differ across different sectors, such as health, social care, banking and others?**

There were not dedicated resources to translate the law into clinical practice. Clinicians find interpretation complex and challenging, particularly in the acute sector where care needs are constantly changing and decisions are often very complex. Knowledge is patchy across all agencies and services and for people working in those agencies. There is also a difference between knowledge and implementation into everyday practice.

All general and paediatric nurses should be given concept of least restrictive in all core pre-registration training, plus those nurses coming from overseas to practice within England and Wales, plus agency staff. It doesn’t need to be aligned with MCA but the concept of least restrictive practice needs to be core.

All 5 principles should be embedded throughout pre-registration training for medical, nursing and AHPs. It’s more about the attitude and approach to the patient than whether they have capacity or not.

There has been no campaign for the public and or patients and families i.e. publicising. On TV/papers for LPA Advanced Decisions etc.

Needs to be more guidance what people can charge – prevents some people from applying for an LPA e.g. solicitors charging.

Due to lack of a publicity campaign banks do not necessarily know what they need to produce for them to evidence people who they say they are. Also declarations of LPA offer no clarity around what is authentication process.

Statutory agencies have to continue to prompt and remind private providers e.g. care homes to consider & evidence the MCA. Staff are still finding many care staff who know nothing about MCA or its requirements including LPA; advanced decisions.

One obstacle to implementing the MCA within practice is it’s not seen as an integral to everyday work. It is also considered that there is insufficient clarity on implementing capacity and resulting best interest decisions for a plan of care. This has sadly become an enormous administrative task rather than a meaningful and personalised assessment.

Training focussed on the legality of the Act – It left us overwhelmed with the knowledge required and the style it was delivered. It should have given less information and focussed on consent and the route we go through - it could have been delivered differently, more effectively. Kent County Council training offers training which is ‘user friendly’ and very much centred on the ‘spirit of the Act’, this is not the case with all training being offered.

6. **Is the Act widely known and understood by those who are directly affected by it and by their non-professional carers? To what extent does the Act provide protection and reassurance for informal carers? Has the right balance between struck between protection of the carer and protection of the individual lacking capacity?**

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7. **Has the Act ushered in the expected, or any, change in the culture of care?**

This has started but the paternalistic, medical model of care is still dominant in health services both in the community and hospitals.

The public seem to have little knowledge of it. There should have been a national campaign when the Act was launched. There is some significant change especially for practitioners working with people with learning disabilities but there is a long way to go for people working with other client groups. People who use services are not aware of it nor are family members. A classic example of this will be when someone is prevented from leaving a ward or a care home because they are ‘confused’. This is accepted as common practice but who is challenging the legality of this and asking “on what authority are you preventing P from leaving and why?” If service users and carers know about the MCA then they can challenge the paternalistic culture of care which is still very much in practice. A controlling culture of care still exists, particularly in care homes, and it is suggested the CQC does not recognise this adequately.

8. **Is there any evidence that the provisions of the MCA affect some groups disproportionately? If so, what data exists to compare representation across different socio-economic groups, Black and Minority Ethnic groups, and gender?**

The Learning Disability sector seems to have the highest level of awareness of the MCA but it is markedly lacking amongst care home for older people. Mental health wards continue to consistently show a disregard to the MCA and its principles.

9. **Are those directly affected by the Act being enabled and supported to make decisions for themselves to a greater or lesser extent than they would have been in the past? Does the means by which the decision is made – ‘general authority’, Lasting Power of Attorney, deputyship, Court of Protection – affect the quality of decision making?**

   Not necessarily. It seems to depend who was given that authority. Evidencing that a person really has an LPA is often difficult. We have experienced people being told there is no LPA when actually there is.

   There are still problems with the views of families taking precedence over the wishes of the person who lacks capacity to make some decisions. Some decisions appear to be made in the best interests of the relatives and only where there are serious risks does this get picked up through safeguarding to be challenged.

10. **What evidence is there that advance decisions to refuse treatment are being made and followed?**

   Very little evidence. Staff often fail to ask about them and service users are not generally being asked about them nor supported to discuss or write them. GPs need to consider...
these with patients in clinic and care homes ought to have discussions with residents about writing one if the person has ever expressed a desire to refuse specific medication.

11. Has the MCA fostered appropriate involvement of carers and families in decision-making?

It has to a limited extent and it is getting better. It is hoped it has but not much evidence is seen in some cases whereas in others the carers/families take over decision making inappropriately. Family members and carers are encouraged and empowered by Chapter 5 of the Code of Practice and their right to be consulted if appropriate and practicable to do so. But how many carers actually know about this? How does the government suggest family members/carers will know about their rights under the MCA?

12. Has the role of the Independent Mental Capacity Advocate (IMCA) succeeded in providing a voice for clients and an additional safeguard against abuse and exploitation for those who have no-one to speak on their behalf?

Yes. They do a good job. The IMCA role has been helpful but there is concern that the hope that this would lead to more general advocacy being available and used more widely still has a way to go.

13. Has the level of referrals to IMCAs met expectations? What are the reasons for the regional variations in the number of referrals?

The numbers continue to increase locally, particularly when practitioners discover that the role of the IMCA exists. There does need to be wider use of advocacy in all services however.

14. Are IMCAs adequately resourced and skilled to assist in supported or substituted decision making for people lacking capacity?

Our IMCAs have been well trained and support the decision making process and they challenge if they believe the decision maker is not acting in the best interests of the person.

Deprivation of Liberty Safeguards

15. Are the safeguards in the Deprivation of Liberty Safeguards (DoLS) adequate?

16. Are the processes for authorisation, review and challenge of DoLS sufficiently clear, accessible and timely?

They are adequate for what they currently offer but need to be changed so that the requirements that exist within DoLS extend beyond the DoLS process so that Managing Authorities can be challenged to provide better care generally. DoLS need to offer a definition of ‘deprivation of liberty’ in the same way the MCA offers a definition of ‘restriction of liberty’.

We are not confident of the understanding of MCA (even less of DOLS), even after 6 years of implementation, amongst different organisations, especially certain professionals such as doctors.

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GPs and consultants, as well as non-professional carers and families. The culture of care which is embedded within different organisations is difficult to shift. More legislative / enforcement powers would be helpful to raise the standing of this important piece of legislation.

Social and health care for vulnerable people with complex needs often involves the use of restrictive measures, with limited understanding of restraint in relation to compliance with MCA. The statutory principles of the least restrictive option and best interests are not understood and applied in practice. The DoLS process currently tends to be largely reactive, i.e. the Supervisory Body responds to DoLS applications made. Failure to comply with MCA and DoLS should carry sanctions for both Managing Authorities and Supervisory Bodies. It would be helpful to extend regulatory powers outside of CQC to professional registration bodies. Professional registration should highlight and help to reinforce best practice in relation to compliance with MCA and DOLS. Social and health care organisations are slow in approaching the Court of Protection because of the cumbersome process and the time delay often experienced. The Court process, which is an important safeguard for vulnerable people, should be made more accessible for organisations as well as members of the public. Families have limited understanding of DOLS and therefore of the safeguarding role they could play in relation to vulnerable people, including their role as RPRs.

In the main I think the principles of MCA (excluding DoLS) are sound and could be implemented easily. Sadly these are not always in place and some areas will need ‘spoon feeding’.

DoLS is open to interpretation and its use is so varied so many remain confused by the difference between restriction and deprivation of liberty. The level of security/locked doors is so common place and expected by staff and family in most care settings that they face criticism if “some one escapes”. The PCT frequently asked for mental health wards to have higher garden fences when detained patients “escaped” with little consideration that these same wards had many informal patients.

DoLS certainly needs updating but not removed as it has provided many people with good safeguards. I do think the CQC should reconsider how they view a deprivation of liberty. When you read the CQC list of reportable issues they are all negative events with DoLS mentioned in the middle of their list. DoLS must not be seen as a failure of services if evidenced that it attempts have been made to avoid a deprivation. I think this is being lost in translation somewhere.

The Court of Protection and the Office of the Public Guardian

17. Are the Court of Protection and the Office of the Public Guardian sufficiently understood and accessible to all? Are they operating effectively and successfully?

There seems to be a sense of ‘mystery’ around the Court of Protection and OPG. This needs de-mystifying by the government in order for it to be seen as an accessible service for advice as well as decision making. Those who have had dealings with the Court and the OPG will be knowledgeable but this is not widespread. They are accessible (if you know they are) but are costly and maybe the cost may affect their use! It is believed that we need to take more cases to the Court more quickly to a timely resolution

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18. What has been the impact of the introduction of Lasting Powers of Attorney (LPA), especially with regard to decision making on matters of personal care and welfare?

Very little. Most people do not have one. The cost of getting one limits access. People do not think about putting this in place until it is too late.

It’s also believed the potential of MCA in enabling and empowering people to plan ahead in advance of loss of capacity is not sufficiently tapped. Again, practitioners tend to focus on the latter end of the process where people lack capacity and decisions have to be made, where potential earlier opportunities of supporting decision making, gathering wishes and feelings, supporting appointment of attorneys and consideration of advance decisions etc., are often lost. This results in best interests decisions which are often driven by family agendas and organisation resources.

Although the numbers of Health & Welfare LPAs and Property & Affairs LPAs are on the increase, we often come across families where such attorneyships are applied for and they have very limited understanding of what they really mean. Families and carers of vulnerable people who have deteriorating capacity, need to be facilitated to be involved in advance care planning.

19. What concerns, if any, are there regarding the costs associated with registering an LPA, or with making an application to the Court of Protection?

Many people cannot afford it as £130 per application is expensive. Why is this cost there? Surely we need to be encouraging people to apply for LPAs if this is important to them not discouraging them by having a fee of this extent attached to it. Also the FSA need to be regulating what solicitors charge for applying for this as they only follow the same process as the person.

20. Is legal aid available and sufficient? What impact will the recent and proposed reforms to legal aid have?

Legal aid is not widely understood and the changes to this by reducing access to it is despicable. How can individuals and families access legal support under the MCA with no access to affordable representation?

Regulation

21. Is the role of the Care Quality Commission in inspecting on the MCA standards adequate and appropriate? Is there a case for additional powers?

It is considered that CQC inspectors struggle to understand some of the highly complex cases that are dealt with in the acute sector and the pressures on staff which are not the same as care homes. There is also concern that the CQC are advising care providers incorrectly on the provisions of the MCA. It is accepted that post-Winterbourne the culture of care required an urgent overhaul but this seems to have come at a price for the vulnerable adult as care homes, in particular, are being asked so show evidence of capacity.

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assessments on a regular basis. Why? Why are people having their capacity assessed weekly (as some CQC inspectors suggest)? What is the person having their capacity assessed for and why? This reaction appears to be making the legalistic functions of the Act a bureaucratic process rather than embracing the spirit of the Act which is to enable and promote people to make decisions. It is also suggested that the CQC do not understand enough about restriction of liberty and DoLS

22. Should other regulatory bodies, such as health and social care professional regulators, be acting in this area?

Yes. Service users, case managers and family members/carers should also be involved in the inspection process in order to bring wider knowledge and expertise to this important role.

Other legislation

23. How well is the relationship with the mental health system and legislation understood in practice?

People really struggle. Consultants still think only psychiatrists can do a mental capacity assessment, which rather says it all!

The working relationship between MCA and MHA needs to be better understood and developed. Mental health professionals in both health and social care need to embrace MCA/DOLS, through training and professional development. Approved Mental Health Professionals require encouragement to apply the MCA in practice.

Devolved administrations and international context

24. Does the implementation of the Mental Capacity Act differ significantly in Wales?

25. What lessons, if any, can be learnt from the approaches taken to mental capacity legislation in Scotland and Northern Ireland, or in other jurisdictions?

26. Is the MCA compliant with the United Nations Convention on the Rights of Persons with Disability (CRPD)? Are there lessons that can be learnt from the CRPD for the successful implementation of the MCA?

Contributors to the call for evidence on behalf of the Kent & Medway MCA Local Implementation Network:

Tina Draper – Kent & Medway Safeguarding Team
Matt Graham – MCA Training Consultant, Kent County Council
Annie Ho – MCA & DoLS Lead, Kent County Council
Sally Hyde – Head of Adult Safeguarding, East Kent Hospitals University NHS Foundation Trust
Marilyn Kitchenham - DoLS Team Manager, Medway Council
Rosetta Lancaster – Kent & Medway Safeguarding Team
Carol McKeeough – Safeguarding Adults Policy and Standards Manager, Kent County Council
Lisa Sheridan – Senior Practitioner, Kent & Medway DoLS Office
Phil Smith – MCA Lead, Kent & Medway NHS & Social Care Partnership Trust

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We write on behalf of the Department of Psychological Medicine, Institute of Psychiatry, King’s College London in response to the Call for Evidence recently issued by the House of Lords Select Committee on the Mental Capacity Act 2005. The department has research interests in mental capacity and related areas. It has clinical activity particularly in liaison psychiatry, acute care psychiatry, neuropsychiatry and eating disorders. We welcome this opportunity to provide evidence for this important review.

We give clinical views relating to the committee’s questions on “overview and context”. In addition, we give 3 research-related recommendations to the committee. These relate to the committee’s questions on DoLS, compliance of the MCA with the CRPD (question 27) and implementation (training).

1. We recommend that the committee question whether DoLS is fit for purpose.

2. We recommend that the committee question whether “de-linking” disability from decision-making ability in the MCA’s test of mental capacity will solve concerns about CRPD compliance and we encourage the committee to consider whether de-linking may introduce unintended health discrimination.

3. We recommend that training resources should be directed toward capacity assessment for clinicians.

A fuller account of our reasons for these recommendations, and the references for our research they draw on, is given below.

Yours sincerely,

Dr Gareth Owen
Clinical Senior Lecturer and consultant psychiatrist

Dr David Okai
Clinical Research Fellow in neuropsychiatry

Dr Ruth Cairns
Consultant Psychiatrist

Dr Sean Cross
Consultant Psychiatrist

Dr William Lee
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Dr Charlotte Wilson Jones  
Consultant Psychiatrist

Professor Matthew Hotopf  
Professor of General Hospital Psychiatry and consultant psychiatrist

Submission from the Department of Psychological Medicine, Institute of Psychiatry, King's College London

Overview and context – clinical views

Our clinical experience indicates that in most situations the basic tenets of the Act are helpful, particularly the distinctions made between mental capacity assessment and best interests. There are however a few areas where concern has been expressed:

1. The Act has not replaced the need for clinicians to be able to make nuanced assessments of mental capacity taking account of the patient’s predicament and the context in which healthcare is delivered. Clinicians have expressed concern that health professionals (particularly those without backgrounds in mental health) use the Act to presume capacity in vulnerable patients whose decision making may be questionable and, perhaps in a reaction to avoid the charge of paternalism, make potentially discriminatory decisions which effectively deny vulnerable and incapable patients treatment.

2. There is considerable concern about the implementation of Deprivation of Liberty Safeguards. Clinicians find it hard to know when DOLS should be used, how the law interacts with the Mental Health Act and suspect that in many instances DOLS are implemented in an inconsistent manner.

3. Clinicians acknowledge that the Act has made assessment of capacity far more clear. However the “use and weigh” ability is perceived to be somewhat slippery and difficult to apply. Psychiatrists feel strongly that the Act needs to include “use and weigh” and avoid a formulation of capacity which is too skewed to cognitive abilities such as memory and understanding, but acknowledge that the underpinnings behind “use and weigh” are less clear-cut. There is a need therefore for further research in this field.

Recommendations – research related

1. Deprivation of Liberty Safeguards (“DoLS”)

Schedule 1A, detailing eligibility for DoLS, was inserted into the Mental Capacity Act (2005) (“MCA”) by the Mental Health Act (2007) after the structure of the Mental Capacity Bill had been designed by the Law Commission and scrutinised by Parliament. In our experience psychiatrists have found these rules very hard to interpret. This impression was confirmed by empirical research we have conducted investigating the “inter-rater reliability” (degree of agreement between assessors) for DoLS eligibility.

Four professional groups: eminent mental health lawyers, consultant psychiatrists, best interest assessors and independent mental capacity advocates (IMCAs) were asked to assess whether a deprivation of liberty had occurred in a number of clinical vignettes based on real-life patients. Our study indicated that there was no consistency of opinion between experts.
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This poor reliability was not a consequence of lack of familiarity with DoLS law.

Reference:


Recommendation

We recommend that the committee question whether DoLS is fit for purpose.

2. Mental Capacity and discrimination

We have conducted empirical research on mental capacity assessment in medical and psychiatric settings. In contrast to the findings on eligibility for DoLS, we have found that inter-rater reliability can be excellent. Structuring the assessment and integrating it into a clinical interview improves reliability and the judgements do not show independent associations with age, sex, educational status or ethnicity. So, on traditional indices of equality, assessment of mental capacity using the MCA framework is reassuring.

The UK has ratified the UN Convention for the Rights of Persons with Disabilities (CRPD). This new international human rights instrument raises questions about whether mental health law (not only the MCA) is compliant with its provisions. One question is whether the MCA test of capacity is compliant with the CRPD’s definition of discrimination. The CRPD defines discrimination on the basis of disability as:

"any distinction, exclusion or restriction on the basis of disability which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms in the political, economic, social, cultural, civil or any other field."

Judgements of mental capacity show associations with mental disorder (a disability in CRPD terms). The associations vary in strength according to the kind of disorder. Furthermore, decision-making abilities similar to those recognised by the MCA in section 3(1) vary according to kind of mental disorder. So, for example, in disorders such as dementia and delirium (common in the general medical hospital) the abilities to understand and reason with relevant information are at risk whereas in disorders such as psychosis and severe affective disorders (common in the psychiatric hospital) the abilities to understand and appreciate relevant information are at risk. This suggests that kinds of mental disorder psychiatrists identify and the decision-making abilities the law seeks to safeguard have links. Refining our understanding of these links in mental disorders ranging from reactions to severe stress to acquired brain injury is a relatively new area of research. Understanding how capacity assessment integrates into the “doctor-patient relationship” is also early in its development.

Some commentators are calling for a “de-linking” of disability from decision-making abilities in order to make the MCA compliant with the CRPD. The suggestion is that rather than the current “two stage” test of capacity in the MCA - where decision-making inabilities must be shown to be “because of” an “impairment of, or disturbance in the functioning of, 

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the mind or brain” (S.2(1)) - there should only be one stage: the assessment of decision-making abilities. The argument is that the because-of-impairment stage introduces a discriminatory link with disability. We caution against this “de-linking” for two reasons.

The first reason is empirical and pragmatic. As above, there is evidence of links between types of mental disorder recognised by psychiatry and the time and issue-specific decision-making inabilities recognised by law. We are not at the stage of knowledge where we can replace current psychiatric classifications with classifications of decision-making inabilities. Even if achieved, it seems to us the classification would still be a classification of disability (inabilities to decide) that would qualify certain rights and freedoms. We think de-linking may risk reducing the reliability and validity of capacity assessments as we can currently achieve them.

The second reason relates to article 25 of the CRPD - right to health.

“States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation.”

Subsection b) clarifies that state parties shall:

“Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons” (italics added)

We would see the MCA as integral to health services needed by some persons with disabilities specifically because of those disabilities. For example, providing for frontline awareness of mental capacity principles on an orthopaedic ward specifically because of delirium we would regard as integral to ensuring persons with delirium have access to health services. It is not uncommon in our experience for people with disabilities to not receive healthcare because choices are taken at face value. Similarly for A&E because of reactions to severe stress. We wish to emphasise this does not imply all persons with these mental disorders will lack decision-making capacity for all health decisions (our data show this is not the case even in people admitted acutely to psychiatric hospitals), but even if they do, that their current preferences are not to be considered with regard. But de-linking could de-link the MCA from the groups that need its safeguards with the possible effect of impairing those group’s right to health. In trying to avoid discrimination against persons with disability by de-linking mental capacity assessment from disability, unintended health discrimination may be introduced.

References:


In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
5. UN Convention on the Rights of Persons with Disabilities 2006

Recommendation

We recommend that the committee question whether “de-linking” disability from decision-making ability in the MCA’s test of mental capacity will solve concerns about CRPD compliance and we encourage the committee to consider whether de-linking may introduce unintended health discrimination.

3 The need for training.

Research in our department has shown that capacity assessments occurring in frontline practice, though increasing, are often approached in a manner that is inconsistent with the MCA. Other research has shown that capacity assessment, when structured and integrated into the clinical interview, can be reliable in medical and psychiatric settings and accord with the principles of the MCA. Ongoing research is also detailing links between different kinds of mental disorder and decision-making abilities thereby building bridges between psychiatry and law. Since the introduction of DoLS considerable training resources have been directed to DoLS assessment. Yet given the evidence that experts find this area confusing training is unlikely to transfer knowledge to frontline practitioners. We think that directing training funds toward capacity assessment will be more successful at achieving knowledge transfer and cost effectiveness.

References


Recommendation:

We would suggest that training resources be directed toward capacity assessment.

2 September 2013

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Professor Celia Kitzinger (University of York) and Professor Jenny Kitzinger (Cardiff University) – Written evidence

From: Professor Celia Kitzinger, Department of Sociology, University of York
Professor Jenny Kitzinger, JOMEC, Cardiff University

About us

We are both social science professors with established research careers in the area of health and communication. We are the founding Co-Directors of the York-Cardiff Chronic Disorders of Consciousness Research Centre – an interdisciplinary group of scholars across two universities carrying out research on the historical, sociological, ethical, legal and economic aspects of coma, the vegetative state and the minimally conscious state. More information is available on our websites at:
http://www.york.ac.uk/sociology/research/current-research/chronic-disorders-of-consciousness-research-centre/) and
www.labwales.org.uk/jomec/research/consciousness/index.html

This submission focuses on the implementation of the Mental Capacity Act 2005 in relation to those in long-term vegetative or minimally conscious states. This is a relatively small group of people - perhaps 5000 people in England and Wales. These people have no capacity to make any significant decisions for themselves. They cannot represent themselves in this consultative exercise, nor are they adequately represented by disability groups speaking on behalf of those who have (some) capacity.

We have carried out a review of the literature in this area and have collected a unique data set of 51 in-depth narrative interviews with family members of people in England and Wales who are – or have been – in either a vegetative or a minimally conscious state following severe brain injury. We also have a supplementary data set of 10 interviews with professionals working in the field. We have analysed these data from various perspectives, particularly for what it reveals about family experiences of the Mental Capacity Act and the Court of Protection. We have received funding from the Wellcome Trust and from the Economic and Social Research Council. We are currently preparing a unit on chronic disorders of consciousness for the charity website HealthTalkOnline (http://www.healthtalkonline.org). Celia Kitzinger is also Principal Investigator for an ESRC Seminar Series on “Advance Decisions: Informing Implementation Strategies through Interdisciplinary and Cross-national Dialogue” (see our website at http://www.york.ac.uk/sociology/research/current-research/kitzinger-advance-decisions/).

We have also prepared a leaflet for families based on our research findings (attached).

We launched this research following our own family’s experience of severe brain injury and Jenny Kitzinger is making a separate submission about her first-hand experience as a court-appointed Welfare Deputy. Our comments here relate only to our academic research findings.

2. Which areas of the Act, if any, require amendment; and how?

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
More clarity is needed about the role of the vegetative or minimally conscious patient’s past values and beliefs in best interests decision-making. Our research shows considerable concern among family members that these are not being taken into account. This concern is reflected in academic commentary by medical ethicists about the judgment in the recent court case concerning a minimally conscious patient (W v M [2011] EWHC 2443 (Fam)).

The Act refers to the patient’s “beliefs and values that would be likely to influence his decision if he had capacity” and to the “other facts that he would be likely to consider if he were able to do so”. Patients in chronic disorders of consciousness are unable to express present beliefs or values, so in best interests decisions it is essential to consider their past beliefs and values, insofar as these can be ascertained from people to whom they were close when they had capacity. The interviews that we have carried out with family members provide very little evidence that family members are being consulted in this way. It was rare, in the acute phase, for family members to feel they had any role in decision-making at all. In particular, their experience was that life-prolonging measures were routinely provided ‘by default’ without any discussion of whether or not the person would have wanted or consented to them. Judicial interpretation (W v M [2011] EWHC 2443 (Fam)) of the role of past values and beliefs as not carrying substantial weight when set against the ‘sanctity of life’ has been heavily criticized by medical ethicists. If ‘sanctity of life’ (which does not appear in the Act) will always trump a person’s prior view that they would rather be dead than maintained with a chronic disorder of consciousness, then people’s own values and beliefs clearly carry very little weight at all.

Our interview research shows that family members are very concerned that the PVS/MCS patient’s previously held beliefs and values should be upheld: some clinicians’ apparent lack of interest in the patient’s beliefs and values, and the failure to include these in decision-making, is a source of anger and dismay.

12. Has the MCA fostered appropriate involvement of families in decision-making?

Our research suggests that in some cases there has not been appropriate involvement of families in decision-making.

Family members in our study report widely differing experiences. There are some clear examples of their having been appropriately involved in decision-making (e.g., as sources of information about what the patient would have wanted) - especially in preparation for Court of Protection cases. There is also some evidence of inappropriate involvement, for example in situations where it may have been the case that medical teams were persuaded by family intervention to act in ways that may not have been in the patient’s best interests – for example, reversing decisions to withdraw/withhold futile treatment in order to avoid conflict with family members. There are also indications in our data that some clinicians may be making premature decisions to withdraw treatment (i.e. at an early stage when the patient’s prognosis is very uncertain and without a proper best interests meeting involving family

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125 Journal of Medical Ethics Special Issue Vol 39(9) September 2013.
members) out of concern to avoid the patient subsequently becoming ‘trapped’ in a vegetative or minimally conscious state\textsuperscript{126}. (This requires further research with clinician interviewees to assess the extent to which this is a problem.)

Overall there was little evidence of family members having been consulted about the patient’s wishes, values or beliefs. Our research suggests that professional understanding of the Act is poor (especially among consultants) and that there are many failures to act in accordance with it. In particular, there seems to be a failure by some clinicians to engage best interests decision-making for unconscious severely brain-injured patients – either in intensive care, or subsequently. For example, one father told us that the attitude of the consultant in the weeks after his son’s brain injury came across to him as “you know nothing; leave it to us; we’re the experts here”. He detailed the medical interventions (bolt, intubation, antibiotics for pneumonia, brain surgeries) provided in the first weeks:

Interviewer: And have you at any point been asked what you as a family think, what information you want?
Thomas: No.
Interviewer: What input you’d like?
Thomas: No. None whatsoever.
Interviewer: Or anything about [son] as a human being, as a person, his choices?
Thomas: No.

Some interviewees reported that their relatives had been maintained in vegetative or minimally conscious states for many years without consultants raising any questions as to whether or not the person would have wanted ongoing life-sustaining treatment. In such cases medical treatments, including artificial nutrition and hydration, are being given not only in the absence of consent (since the person lacks capacity) but also the absence of adequate best interests decision-making meetings to establish what the person’s prior values and beliefs might have been in relation to continued treatment.

Families typically find it difficult to raise the possibility of withholding or withdrawing treatment (‘I’d feel like a monster’) – and it is not their legal responsibility to do so. However, in the absence of best interest meetings, some of our interviewees had attempted to initiate a conversation about the possibility of withdrawing or withholding life-prolonging treatments and had then been obstructed by health care professionals. A couple interviewed together described what happened when one of them (Harry) attempted to question what was happening to his sister who was in a permanent vegetative state:

Harry: Apparently after one year they’re supposed to come and ask you, you know what do you want to do, and that never really happened.

Natalie: Well it didn’t happen at all. It was the opposite. On one occasion […] Harry asked the nurse in charge “Why is this being allowed to continue?” And this particular nurse said

“What do you know?” Harry said, you know, “She’s not coming out of this is she?” And she [the nurse] said, you know, “Are you a professional? You’re in no position to judge this!” and really took him to task in a way that was totally inappropriate.

Another interviewee recalled how she was treated when she tried to ask what could be done differently for her husband in a permanent vegetative state.

I said ‘What if I don’t want this anymore?’ And he [the consultant] immediately responded saying ‘You’d go to prison’. I think maybe they were giving him antibiotics… I felt they were saying, ‘You can’t do it’. And then I just felt, ‘God, is this going to go on forever and forever?’

In such cases the opportunity to hold a best interests meeting about treatment withdrawal has clearly been missed.

It is very likely that non-compliance with the MCA requirement for best interests meetings means that medical treatments are being delivered to patients who would have refused them if they could, and for whom continued treatment is not in their best interests. Research evidence indicates that most people would not consent to life-prolonging treatment if they were in a permanent vegetative state (PVS) or minimally conscious state (MCS). Extrapolating from this survey suggests that many people currently in a PVS or MCS would have held the view that if they were to be in such a state they would wish treatment to be withdrawn. This is supported by our interview research in which about three-quarters of our interviewees say that their relative would not wish to be maintained in this state. The fact that some PVS patients are being maintained for many years after their families believe they would rather be dead and without any consultation with their families about this is not compliant with the MCA. It also means that doctors are actively involved in giving futile medical treatment. According to the Royal College of Physicians:

When the diagnosis of a permanent VS has been made by establishing the cause of the syndrome so far as possible, by confirming the patient’s clinical state and by the passage of time, recovery cannot reasonably be expected, and further therapy is futile. It merely prolongs an insentient life for the patient and a hopeless vigil entailing major emotional costs for relatives and carers.

Some interviewees had the impression that they, as ‘next of kin’, were responsible for decisions about withdrawing/withholding treatment. They described having been asked for ‘consent’ for particular treatments and sometimes reported that serious medical decisions had been reversed after they had withheld consent. This is not legally correct – and it is not clear from our data whether some clinicians are in fact giving families decision-making

127 Demertzi , A. et al, Attitudes towards end-of-life issues in disorders of consciousness: A European survey, Journal of Neurology 258: 1058-1065. This survey of 2,475 health care professionals across Europe found that 82% of respondents would not want to be kept alive in a permanently vegetative state and 67% would not want to be kept alive after one year in a minimally conscious state.


129 RCP guidelines, 2003 s. 3.5
powers that are not legally theirs, or whether families misunderstand the situation. What is clear is that interviewees who believed (whether correctly or not) that they had decision-making rights over withholding or withdrawing treatments felt burdened by the responsibility of making life or death decisions for a loved-one, and were usually left without any support in making these decisions. Research shows that under these circumstances there is likely to be a bias towards overtreatment, as families respond by choosing whichever treatment option minimizes their own sense of responsibility. Clinicians should make clear to families that they are not the decision-makers (see our leaflet for families, submitted separately, which explains this). Clinicians need to take the lead in calling properly convened best interests meetings and making clear to families that it is the clinician (or, in ANH withdrawal cases, the judge) who is the decision-maker.

Our findings suggest the importance of regular meetings to discuss patient best interests, with the initiative for raising issues of treatment withdrawal coming from the clinicians. It might also help if ANH withdrawal (e.g. for PVS patients after one year) were possible where there is consensus between clinicians and families, without requiring a court to authorize the decision. Some bioethicists argue that once a PVS diagnosis is confirmed then (in the absence of any advance stated wishes to the contrary) withdrawal of ANH should become the default position with the burden of justification on those who would continue ANH.

There is also a need to clarify the circumstances – if any - under which a person who is in a MCS can be allowed to die. Some commentators have pointed out that it may be worse to be in a minimally conscious state than in a vegetative state. The judgment in W v M [2011] EWHC 2443 (Fam) has led to a widespread perception that the law will not permit withdrawal of artificial nutrition and hydration from these patients. This may mean that instead of a managed death from ANH withdrawal with appropriate palliative care as authorized by the courts MCS patients are allowed to die instead from disease and infection, or even from ‘mercy killings’ (mentioned by many of our interviewees).

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130 A study in Scotland found that 88% of relatives of intensive care patients falsely believed that they already had the right to consent on behalf of an incapacitated adult. The authors observe “It was our impression that not all doctors were entirely clear on this either” (Booth, M.G., et al, 2004, Relatives’ knowledge of decision-making in intensive care, Journal of Medical Ethics 30: 459-461).


134 Kitzinger, J. & Kitzinger, C. 2013. The ‘window of opportunity’ for death after severe brain injury, Sociology of Health and Illness 35(7): 1095-1112. doi: 10.1111/1467-9566.12020. There have been two recent reported cases of ‘mercy killings’ of PVS patients by family members: Francis Inglis killed Tom Inglis, her VS son, and is serving a murder sentence (R v Inglis [2010] EWCA Crim 2637; Tudor David killed Diane David, his PVS wife, and also himself (http://news.bbc.co.uk/1/hi/wales/10539093.stm)

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11. What evidence is there that advance decisions to refuse treatment are being made and followed?

Our research\textsuperscript{135} shows that there is a lack of knowledge about advance decisions even among individuals who are exceptionally highly motivated to ensure that they are not kept alive in a permanent vegetative or minimally conscious state. Our interviewees were virtually unanimous that they would not want to be kept alive in a state such as that of their relative – but only 30\% had written advance decisions refusing treatment. The main reason given for not having written one was not knowing that such a thing was possible. Some interviewees also believed that ‘next-of-kin’ were legally entitled to make decisions on their behalf, and would ensure that their wishes were respected.

Our interviewees reported that advance wishes about end of life care had been communicated to them, but rarely in a form that meets the legal requirements for a valid Advance Decision (AD). The introduction of statutory support for ADs (via the MCA) should not mean that prior wishes and beliefs that do not fulfill the legal requirements for formal ADs are given any less weight than under previous common law. In our research only one family reported that the patient had made a valid AD, and in this case, although the family members were certain that he intended it to cover his current circumstances and would have wished to refuse treatment, the AD was found (by the treating clinician) to be not ‘applicable’ to the particular circumstances of treatment refusal. In another case, the written advance refusal of treatment was in the form of a letter and not witnessed, and so not legally valid.

A written statement about what a person would want is valuable for families even if it does not constitute a valid and applicable AD:

I think the fact that he’d written what he wrote helped you cope with it in your head. Because otherwise it would feel like it was more your decision. I mean, it’s going to be hard anyway, but it’s going to be – it would have been so hard to live with that, knowing that – almost feeling that you’d sentenced them to death, however much they wanted it.

One interviewee, whose relative was in a vegetative state following complications from surgery reflected on a missed opportunity to promote ADs at the point of gaining informed consent for that surgery:

Mary: In hindsight, looking back at what they actually said, frightening him to death literally, him thinking, “oh my God, I’m going to die”, that maybe - if they're going to say that anyway to make sure that they're warning people of every possibility - why don’t they suggest that they write the advanced letter is it called?

Int: Advance Decision.
Mary: And maybe give them a leaflet regarding it. Suggest, ‘Look, why don’t you think about doing one of these just in case you can't communicate and then we know exactly how

\textsuperscript{135} Kitzinger, C. & Kitzinger, J. 2013. A fate worse than death? End of life planning, severe brain injury and chronic disorders of consciousness, Talk to Practitioner Research Network Meeting, Sue Ryder Care Centre, Queens Medical Centre, 31 January. Downloadable slides at: http://www.york.ac.uk/media/sociology/research/currentresearch/kitzingerconsciousness/Kitzinger%20ADs%20and%20CDoCs%20Sue%20Ryder%2031%20Jan%202013.pdf

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You feel and how – what you would want us to do should you not be able to communicate. Say for instance, say if you were in a coma immediately afterwards, it might be just a temporary thing but we won’t know whether you’d want this or want that.

Our findings suggest that ADs have not been sufficiently promoted and that some of those who would very much want to refuse treatment in advance of losing incapacity are missing out on the opportunity to do so because ADs have not been brought to their attention. It is also of some concern that to find that in two families in our sample the person had attempted to draw up a legal document (in one case with the assistance of a solicitor) to ensure their wishes were met and that in neither case did the supposed ‘AD’ lead to the outcome that the family believed the person would have wanted. If this is widespread, it suggests the need for training of training in the preparation and interpretation of ADs among both solicitors and clinicians.

13. Has the role of the Independent Mental Capacity Advocate (IMCA) succeeded in providing a voice for clients and an additional safeguard against abuse and exploitation for those who have no-one to speak on their behalf?

There was no involvement of IMCAs in any case in our sample. Since families (in most cases) say that they were not given the opportunity to provide a voice for their patient or to speak on their behalf – at least for some period of time - this may have meant that the PVS/MCS patient was left completely without representation.

18. Are the Court of Protection and the Office of the Public Guardian sufficiently understood and accessible to all?

No. We consistently find that even academic audiences are surprised that next-of-kin cannot make decisions for another adult. This erroneous belief is one reason why people either do not write Advance Decisions (i.e. ‘my family knows what I want’) or do not appoint an LPA for Health and Welfare (since they believe the spouse or adult daughter who they would wish to make decisions already has decision-making rights)\(^\text{136}\). There is also a widespread confusion between LPAs for finance and for health, with many believing that the former accord the person decision-making rights over health and welfare.

Please see link attached.

The role of family and friends in medical decisions

1 September 2013


In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Jenny Kitzinger – Written evidence

About me

I am a Court appointed Welfare Deputy (and also Finance Deputy). This evidence is based on my experience of being a sister, and then court appointed Welfare Deputy, for ‘P’ while she was in a vegetative and then a minimally conscious state. She had suffered severe brain injuries in a car crash in 2009 and lacked capacity to make any medical treatment decisions for herself.

My application for Welfare Deputyship was fully supported by written testimony from P’s parents, partner, siblings and friends who all agreed she would have chosen me to represent her. I have continued to consult with P’s family/friends and there has been no dispute about what P would have wanted.

Q6 Is the Act widely known and understood by professionals required to implement it? How does this differ across different sectors…?

1. (Re. Q6) The health professionals I dealt with did not appear to understand the need to consider P’s prior expressed values and beliefs when making ‘best interests’ decisions about her, and subsequently also failed to seek consent under the terms of my appointment when I became her Welfare Deputy. An internal investigation in response to my subsequent complaint against the Trust found significant failings. The following quotations in italics are from that internal investigation. It found, I quote, ‘significant failings’ including: (a) in relation to ‘best interests’: ‘failing…to have actively sought out information regarding [P’s] previously expressed wishes, beliefs and values to inform future treatment and care decisions’, ‘to provide [P’s] partner/family with sufficient information…to enable them to participate appropriately in respect to health and welfare decisions in respect to [Ps’] best interests’, and ‘failing…to document how [P’s] best interests were determined’. (b) in relation to treatment without consent (after Welfare Deputy appointment), the investigation found failures to ‘give prior (sometimes any) information to the Welfare Deputy regarding several investigations and treatment decisions’ and failings ‘to seek consent for a majority of treatment and care decisions…’. The report concluded: ‘These failings highlight a general lack of understanding amongst professionals about the Mental Capacity Act 2005 and…the Code of Practice, and especially about the role of court appointed Deputy…’. The report concluded with a 12-point action plan that was needed to address the issues raised.

2. (Re. Q6) In comparing my experience across sectors - there was least knowledge or understanding of the Act among senior clinicians in the health sector, but it was better in social care and banking. The best experience I had was with a staff member at Nat West who was well informed about my role as finance deputy (and efficient, compassionate and enabling). Other banks, however, are slow and very difficult to deal with - my worst experiences have been with an internet bank.

Q10. Are those directly affected by the Act being enabled and supported to make decisions for themselves to a greater or lesser extent? Does the means by
which the decision is made – ‘general authority’, Lasting Power of Attorney, deputyship, Court of Protection – affect the quality of decision making?

3. (Re. Q10) Re the quality of decision-making: I cannot compare current situation with ‘the past’ as I only entered this area of work in 2009. However, I can say that I do now believe that having a Welfare Deputyship is finally making a difference to the quality of decision-making for my relative. In the context of a new care setting (having moved P out of the original Trust area) and working closely with her new team I feel that the Deputyship allows for (a) clearer lines of communication and representation (b) clearer best interests or consent (as applicable) processes and (c) P’s prior expressed values and beliefs to be taken into account to some extent. In particular my Deputy role was key in relation to insisting on consent to the drugs given to P. As Welfare Deputy I was able to view her medication chart and then challenge a failure to request consent re some medication. This revealed the fact that P had been put on another patient’s medication by error – a situation that had continued for 2 weeks. Given the evidence about the widespread error in medicine prescription/administration in care homes this seems to me a vital way in which decision-making might be improved. I would also note that formal roles such as LPA and Deputies for health and welfare increase the likelihood of conflict of opinion about best interest becoming overt – this is not a bad thing, but there should be mechanisms in place (e.g. mediation services) to avoid this simply escalating straight to the court of Protection (as happened in my case too). This is expensive and stressful and may be unnecessary.

Q12. Has the MCA fostered appropriate involvement of carers and families in decision-making?

4. (Re Q12) Sadly I experienced very limited involvement of carers/families in decision making for the first two years in my particular case (see answer to question 6 re Trust’s admission of failure to appropriately involve family in decision-making). The family had to fight every step of the way to try to represent P’s wishes and have any input in relation to serious medical treatments. Even after I became Welfare Deputy, new medical treatment was initiated without the necessary consent they should have obtained from me under the terms of the court order. In hospital she became ‘their patient’, not a person – a cog in the wheel of the machine, subject to rushed routines and assumptions - an object of ‘best clinical practice’ (or at least ‘business as usual’) rather than ‘best interests’ decision-making. She could not speak for herself and there appeared to be no consideration of what she might have wanted for herself. She was not treated with any respect, as a person with human rights.

Q13. Has the role of the Independent Mental Capacity Advocate (IMCA) succeeded in providing a voice for clients and an additional safeguard against abuse and exploitation for those who have no-one to speak on their behalf?

5. (re Q13) The IMCA service looks great in theory, but I would like to see its remit expanded to include being able to act in cases where there are families – but those families may be disempowered, in shock or out-maneuvered by the system and not having appropriate input. For example, IMCAs would be useful linked to intensive care. In our case, there was in effect ‘no-one to [be heard to] speak on her behalf’ because of failures by the Trust to follow the MCA and consult with family. Although family members were not judged ‘inappropriate to consult’, we were not consulted appropriately. I wonder if an IMCA might have been useful to represent P because we did not know the system and were in trauma.

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from the accident so it was hard to effectively represent her in the face of institutional evasion and obstruction. We also had no status with the treating clinicians and the culture within this setting seemed to be to treat families as volatile and untrustworthy - lacking capacity to represent their relatives’ views until proven otherwise. One of the treating clinicians informed me later that it usually took her about a year to get to know a family and decide whether or not to trust their input. In practice then the default position was to treat family members as inappropriate to consult (at least if they challenged what clinicians wanted to do) until a year after the initial injury. During this time any patient left in a coma or vegetative/minimally conscious state (or with other conditions which render them unable to represent themselves) is then effectively without representation.

Q18. Are the Court of Protection and the Office of the Public Guardian sufficiently understood and accessible to all? Are they operating effectively and successfully?

6. (Re Q18) I did not feel that these bodies operated effectively and successfully in backing up my appointment as a Welfare Deputy. I went to great lengths (time, money, documentation) to obtain the Welfare Deputyship at a time of great trauma when I was stretched in all directions after P’s accident – it was time away from her bedside trying to care for and protect her. When I was awarded the Deputyship if felt like the Holy Grail, something that would make a difference. (Indeed, I was told that the judge who awarded the Deputyship commented that it was ‘a chance to see if this part of the MCA can work in practice’). However, when clinicians simply ignored the court order, there seemed to be no backup to make them take it seriously. I was cast adrift to try to perform this role in a hostile environment with no support from the court. There was a lack of response to my reports that there was a problem with non-compliance with the MCA and requests for guidance about what I should do, and phone calls asking for help, generated no useful response.

7. (Re. Q18) On the basis of my personal experience it seems to me that opportunities to improve the implementation of the MCA are being missed (a) It would be good if the Court could provide backup to Welfare Deputies (and LPA health and welfare) e.g. at least someone who could provide a stern letter from the court to organisations reminding them of the MCA and advising them to self-audit, if deputies allege they are failing to comply with the terms of their appointment; (b) We serve in many ways as informal [IMCA] at the moment, but without the training and support. (I have been to IMCA training and found it useful. I recommend that this is provided free to all Welfare deputies and LPAs for health and welfare); (c) It would be useful if the Court or OPG could offer facilitating mechanisms to ensure sharing of ‘lessons learned’ (other than the expensive and confrontational route of legal action). My own complaint against the Trust for non-compliance with the MCA resulted in the Trust admitting problems and producing a detailed action plan, as well as meeting with me a year after producing the plan in order to review progress against each point. Perhaps this effort between myself and the Trust (and pursuits of complaints by other LPAs and Deputies) could be shared as ‘lessons learned’ with other Trusts? Finally, it also seems to me that we (LPAs and Deputies for Welfare) could be valuable front-line advocates for the MCA. With appropriate backup and networking, we could be potential champions for the MCA – serving as the eyes and ears of the Court on what is happening on the ground, helping pin point problem areas, challenging cultures of non-compliance and acting as levers for change.
In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
Overview and context

1 To what extent has the Mental Capacity Act 2005 (MCA) achieved its aims?

1.1 I wish to bring to your attention the fact that a number of London Boroughs have not been allowed to submit their honest responses to your call for evidence. Your request has resulted in major internal political discussions where Directors of Adult Social Services became fixated with public relations and scrutiny by local councillors. It concerns me that some council officers were prevented from giving you a true reflection of local practice and professional experience, if at all.

1.2 I think the MCA 2005 is excellent and this law is achieving the aims to ensure people who lack mental capacity have their rights better respected than before the law was implemented. This legislation helps to keep people safe and even prevents people at high risk of harm, from premature death by means of the Deprivation of Liberty Safeguards (DoLS). Case Law has made professionals pay attention and service users and their family members are consulted with more, when decisions are needed. I understand that there have been comments about the DoLS and the cost to organisations, but I believe the benefits of ensuring that health and care providers provide good quality care to service users is worth it.

2 Which areas of the Act, if any, require amendment; and how?

2.1 An Urgent DoLS application should be granted automatically for at least 7 working days, not 7 calendar days. I have hardly ever come across cases, having coordinated DoLS for two boroughs and having worked as a private Best Interest Assessor for 7 London Boroughs, where someone is being deprived of their liberty for no good reason. Allowing more time would support the service user to best participate and all their circumstances to be fully considered before decisions are made for their longer-term care and safety.

2.2 Unresolved cases where decisions are needed for someone who lacks mental capacity would be best directed at an appeals panel. Perhaps setting up a similar system to the Mental Health tribunal system would be more beneficial to try and resolve cases locally, rather than going to the Court of Protection which is far removed from citizens.

3 At the core of the MCA are its principles and definitions of capacity and best interests. Are these appropriate?

3.1 I believe the principles and definitions are very good and working appropriately. It was noticed that a number of professionals who carry out mental capacity assessments, quote the first principle of the Act and conclude prematurely that the person has mental capacity. This is mostly the easy way out as professionals then don’t record further about the concern and do not need to take any further action.
Implementation

4 To what extent have the five principles of the MCA been implemented in frontline practice? What evidence is available to assess this? Is there a satisfactory balance between enablement and protection?

4.1 I have seen most practitioners being aware and working in line with the MCA as much as the financial resources and staffing levels within organisations allow. Recording practices can often be a better safeguard for professionals, if used correctly. Councils and organisations are raising awareness locally and care providers often contact their local authority for advice. I have seen many social workers make successful plans to allow people to return to live in the community. Equally when they decide that the community environment is no longer suitable they consult with service users, families and IMCAs more widely before decisions for residential or nursing care is made.

5 How effective was the Government's implementation plan? What measures were taken to ensure that professionals and families of those who lack capacity know about and act in accordance with the provisions of the MCA? Has it led to sustainable change?

5.1 The initial local implementation networks established in London worked well and helped to promote practical application of the law, but unfortunately these groups no longer exist and the MCA is not promoted as much as before. I am concerned that the awareness was not sustainable, as financial resources diminish and grants are no longer ring-fenced, experts are moving away from this specialist area of work. A national public awareness campaign would be ideal, with some television advertisements to inform people of the law. The public don’t know about this legislation and may not want to think about circumstances of when someone loses mental capacity to make decisions for themselves. Citizens and unpaid carers should know about how they could help plan for their or the cared-for person’s future. As a Best Interest Assessor I always find that it takes a lot of time explaining the law and different, relevant elements to people and their families.

6 Is the Act widely known and understood by professionals required to implement it? How does this differ across different sectors, such as health, social care, banking and others?

6.1 The Act is increasingly known and understood by professional groups and people know more now than when the Act was first introduced. A number of professionals still think they know best, without truly listening to the person and consulting with their family or friends. IMCAs are still not fully consulted for Serious Medical Treatment decisions. Some professionals do not understand that they are acting unlawfully by not involving them in such circumstances.

7 Is the Act widely known and understood by those who are directly affected by it and by their non-professional carers? To what extent does the Act provide protection and reassurance for informal carers? Has the right balance been
struck between protection of the carer and protection of the individual lacking capacity?

7.1 Knowledge about the Act is growing, but it is not widely understood. Most people affected by it are unable to understand it, due to the nature of their illness and impairment. Carers are generally pleased about the Act and the safeguards it offers, but some are still uncomfortable with professionals having that level of control.

8 Has the Act ushered in the expected, or any, change in the culture of care?

8.1 People are now more empowered and their wishes and feelings are considered before most complex decisions are made. There has been a shift away from the culture of ‘professionals know best’, but instead professionals consult more with the person, their family and IMCAs allowing for greater transparency in how decisions are made. Possibly more people are supported to continue living in successfully in the community as a result of positive risk taking which was made popular again with this law.

9 Is there any evidence that the provisions of the MCA affect some groups disproportionately? If so, what data exists to compare representation across different socio-economic groups, Black and Minority Ethnic groups, and gender?

9.1 I believe that there is gross discrimination against older people in the provision of care. Many older people never have an opportunity to go out, especially if they did not have family members / friends to take them on outings. Even making use of care home gardens is rarely possible due to low staffing levels. This means that people never have an opportunity to go outside! I recently spoke with a BIA who said she managed to arrange for a service user to go for short outings with her wheelchair and the support of a carer. She reported that the service user was lyrical about the sensation of the wind on her face, saying she thought she would never feel that again. DoLS has often sought to address the gross inequality in the care of older people, who have reduced care packages, compared with younger people with learning disabilities. I think that the most DoLS cases relate to older people as a consequence and that they could be over-represented in statistics?

Decision-making

10 Are those directly affected by the Act being enabled and supported to make decisions for themselves to a greater or lesser extent than they would have been in the past? Does the means by which the decision is made – ‘general authority’, Lasting Power of Attorney, deputyship, Court of Protection – affect the quality of decision making?

10.1 This law has brought power and control back to people with mental impairments, and enables them to participate more in decision-making processes. Best Interests processes and the more independent DoLS process has led to the person, their family members, friends & IMCAs being consulted before decisions are taken. More people are subsequently being discharged from care homes and given other care opportunities in the community.

10.2 When someone is officially appointed to make certain decisions, it reduces the time that professionals have to grapple and weigh options in order to make best interest
decisions. In an ideal world LPAs and deputyships ensure better decisions. It is rare that problems occur that lead to serious safeguarding procedures and to the Court of Protection being asked to intervene. Most people find the different types of LPAs confusing, in that they think Financial LPAs can make health and welfare decisions.

11 What evidence is there that advance decisions to refuse treatment are being made and followed?

11.1 I understand from colleagues in health settings that advanced decisions to refuse treatments are being made and followed. In training nurses and health care staff regarding the MCA & DoLS it seems that people in hospital rarely check whether the person made decisions in the community to refuse certain types of treatment. GPs could do more to raise awareness of advanced decisions with the public.

12 Has the MCA fostered appropriate involvement of carers and families in decision-making?

12.1 Carers and Families are now much more part of decision-making in health and social care settings. It seems that people rarely opt for LPAs or advanced decisions. In general people believe that professionals will make best interest decisions for them, as no one can predict all future circumstances.

13 Has the role of the Independent Mental Capacity Advocate (IMCA) succeeded in providing a voice for clients and an additional safeguard against abuse and exploitation for those who have no one to speak on their behalf?

13.1 IMCAs & paid RPRs are the real Safeguard for people, as they are more independent than the decision maker. A more flexible approach in accessing IMCAs would be beneficial, even when the person is befriended. Some people may have family members who live far away and who are unable to see the person’s current circumstances in relation to the decisions, which have to be made. IMCAs would be often best placed to see the person and liaise with family members.

14 Has the level of referrals to IMCAs met expectations? What are the reasons for the regional variations in the number of referrals?

14.1 Overall IMCA referral levels have met the expectations as far as I know. I am not sure what the reasons are for variations in referral numbers, but I would have thought that good contract monitoring and awareness raising would help prompt practitioners and clinicians to make the appropriate referrals to IMCAs.

15 Are IMCAs adequately resourced and skilled to assist in supported or substituted decision making for people lacking capacity?

15.1 IMCAs and RPRs have been the main Safeguard, not only for the service user, but they help keep professionals in check.

Deprivation of Liberty Safeguards

16 Are the safeguards in the Deprivation of Liberty Safeguards (DoLS) adequate?

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
16.1 The DoLS help keep people safe, helps promote their rights and prevents them from early death. People with high care needs often require specialist placements and care. The DoLS ensures that the person's needs are better met. DoLS provides independent expertise and acts as the belt and braces in care provision. The DOL safeguards allow Supervisory Bodies to check what quality of care is being provided. These Safeguards also highlight which managing authorities provide substandard care.

16.2 DoLS may be an expensive system to run, but the benefits to service users outweigh the cost of the service. DoLS is often needed for people with severe impairment and serious illness. Meeting these needs well, have the highest impact on financial resources as specialist placements and care provision is extremely expensive. The DoLS are only as good as the underlying care planning and practice and the financial resources that support them in the organisations concerned. Keeping DoLS as an independent process from care providers is an additional check on what care providers do.

17 Are the processes for authorisation, review and challenge of DoLS sufficiently clear, accessible and timely?

17.1 The DoLS process is over-bureaucratic. There are ways in which it can be simplified, especially if the official forms could be reviewed. There are approximately 38 forms many of which appeared to request duplicate information. It was felt that some forms could be combined and replaced with a single form. For example the Eligibility Assessment, Mental Health Assessment and Mental Capacity Assessment could all be combined on one form, instead of three separate forms. Some free text space would be best, on Form 10, for BiAs to provide a background summary of information about the person. It would be good to update the Codes of Practice in line with the case law that shaped DoLS practice over the past 4 years. The law must be updated to include a clear definition of what constitutes a deprivation of liberty. The tight legal timescale of 7 calendar days for an urgent application is too short. It provides too little time for all the person's circumstances to be assessed, for family members and IMCAs to be fully consulted, their views considered, reports to be produced and available for signatories to agree or decline the detention.

17.2 Reviews are often not very helpful to challenge DoLS. The review process can take longer than the period for which the detention was initially granted. The Court is considered too far removed from the people and an enhanced review panel would be a better option before considering an application to the Court.

The Court of Protection and the Office of the Public Guardian

18 Are the Court of Protection and the Office of the Public Guardian sufficiently understood and accessible to all? Are they operating effectively and successfully?

18.1 The Court of Protection (CoP) is too far removed from the people, the average citizen does not necessarily want to bother a court with decision making, even when it would be in their best interests. It is very expensive for local authorities (LAs) to
approach the CoP in cases of disputes. LAs would prefer to spend money on service users’ care, rather than approach the CoP in individual cases.

19 What has been the impact of the introduction of Lasting Powers of Attorney (LPA), especially with regard to decision-making on matters of personal care and welfare?

19.1 Although LPAs give people the opportunity to make decisions for when they lack mental capacity, there are few people with LPAs in place. The fact that there are two different types of LPAs is confusing. BIs think that most people want their family members and friends to be consulted, before decisions are made. However people tend to prefer professionals to make decisions, rather than giving their family or friends the responsibilities of an LPA. It is likely that as time passes and future generations become more aware of the Act, that people will want more control of their future and LPAs may be more popular.

20 What concerns, if any, are there regarding the costs associated with registering an LPA, or with making an application to the Court of Protection?

20.1 A number of people, especially unpaid carers are concerned with the application costs of LPAs. Solicitors provide most advice offered about LPAs. Given that applications are made to the court most people think they should make use of a solicitor’s services. The general public may be unaware that they can complete the forms themselves and apply to the Office of the Public Guardian. Unpaid carers have mentioned that the application fees are steep and they are also concerned that the CoP is not always accessible to all. I understand that they find the completion of the application forms complex and time consuming.

Regulation

21 Is the role of the Care Quality Commission in inspecting on the MCA standards adequate and appropriate? Is there a case for additional powers?

21.1 The Care Quality Commission (CQC) has helped to raise the profile of the MCA and providers are taking it more seriously. It would be beneficial for CQC inspectors to be able to raise a DoLS application themselves, like they do with Safeguarding Alerts. Compliance actions should be issued for providers that do not comply with conditions set on a service user’s DoLS. CQC inspectors should observe the person and check the care provided against their care plan.

23 Should other regulatory bodies, such as health and social care professional regulators, be acting in this area?

23.1 Healthwatch and carers’ groups should be given more powers to help regulate services. Although self-assessments are useful, audits are the best way of checking that the MCA is embedded in practice.

Other legislation

24 How well is the relationship with the mental health system and legislation understood in practice?

In order to protect individuals the Committee has chosen in some cases to remove identifying information from the submissions.
24.1 The interface with other legislation was complicated e.g the criteria for the DoLS Eligibility Assessment that seeks to address the overlap between the MCA and MHA, is far too complex. There needs to be a simpler process where, failing the criteria of one law, there is a provision for a seamless assessment under the other.

2 September 2013