



HOUSE OF LORDS

Select Committee on the Mental Capacity Act 2005

THE MENTAL CAPACITY ACT 2005

Oral evidence

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Questions 1 - 24

TUESDAY 18 JUNE 2013

Members present

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

Witnesses

John Hall, Deputy Director of Family Justice, Ministry of Justice, **Nick Goodwin**, Deputy Director of Court Tribunal Fees, MoJ, **Anne-Marie Hamilton**, Deputy Director of the Social Care Quality and Safety Branch, Department of Health, and **Claire Crawley**, Senior Policy Manager, Adult Safeguarding, DoH

Q1 The Chairman: Good morning. I am sorry to have kept you waiting; we had some preliminary business to attend to. Mr Goodwin, if you have any difficulty understanding or hearing what we are saying, please indicate, and we will try to accommodate you as best we can. The evidence session that we are about to begin will be webcast live as well as transcribed. The transcripts will be published on the Committee's website and witnesses will have the opportunity to make minor corrections

and clarifications to the text. I understand that there is no opening statement, but can I just have confirmation of that? In that case, we will simply go to the first question, which is to be put by Baroness Andrews.

Baroness Andrews: Thank you, Lord Chair. I am afraid that I have the blockbuster question on this hugely important Act, which is: to what extent to you think the Act has been a success? Is there a consensus about what is success? Is there a consensus, indeed,

about where there has been failure? Can you say something about the nature of the evidence and the criteria that you use as departmental officials to reflect that?

Nick Goodwin: Thank you. I shall start and pass you over to colleagues at some point. Overall, our view is that the Act has been a success. When it came in, it was certainly widely welcomed as a progressive piece of legislation that balanced protections with empowerment, and that is still largely the case in terms of the core principle of the Act and so forth. We engage with stakeholders, and that is their view. That is the day-to-day dialogue that we have. We have consulted over a few minor changes to the legislation, rules, regulations and so forth to implement the Act. The sense that we have had back from those consultations is that the legislation as a whole is still highly regarded.

How one gauges its success is a bit more difficult. We do not have any hard criteria or measures at the moment, so far as I am aware. The key things you would be looking for are whether the Act is used and understood and whether the accompanying objective of securing culture change has been achieved. In terms of use, yes, the Act is being widely used. Certainly, there is enthusiastic take-up of the lasting power of attorney. There have been about three-quarters of a million since the Act came in, and there is an increase in demand year on year for Public Guardian services generally. We acknowledge that there is probably further demand out there, and at the moment we are trying to put in place measures that allow that demand to be met or captured.

I know that colleagues in Health have done a lot of work on understanding, and I will leave them to explain a little more about that. We believe that the code of practice is still well regarded. It has been purchased by almost 60,000 people as well as being obtained free, so it is out there, and we think it is being used, but again we all acknowledge that understanding is not something that happens overnight, ditto culture change. There are some good examples of where we are now vis-à-vis 2005 or 2007. I know that the Office of the Public Guardian has been talking to the financial industry recently, and banks are now putting into practice means whereby they allow small cash sums to be available to those with questionable capacity whereas larger, more strategic decisions still rest with attorneys and so forth. It is one of the examples in the code of practice, but life is being given to that now, and I think that shows that there is greater comprehension about what the Act means and what the principles mean in some respect. My assessment would be yes, overall, but there is still some progress to be made on understanding and culture change.

Anne-Marie Hamilton: We would say broadly, yes, it has been a success, but as legislation that requires significant cultural change across the health and care sectors, it takes time to embed and to truly see that.

The criteria we use are not formal criteria as such, but we ask whether the Act is understood, whether it is being used, and whether it is having an impact on people. In terms of the hard evidence we have, from data, we can see that referrals to independent mental capacity advocates have doubled in the five years since the Act was introduced. Referrals for deprivation of liberty safeguards have also increased over that time. We would expect best interests and capacity assessments to be taken on a daily basis, but obviously we do not collect data around that.

In terms of the informal evidence we have, we know that most hospitals and local authorities have Mental Capacity Act and deprivation of liberty safeguard leads in their organisations who are responsible for training staff, auditing practice and challenging practice. We know that local networks continue to meet to share innovative practice and discuss emerging case law. We know that the independent mental capacity advocate service is playing a valuable

role in representing people’s best interests. We have significant informal evidence and some data, but broadly speaking, to echo what Nick said, we think we have made considerable progress so far but there remains a lot to be done truly to implement and embed this across the system.

Q2 Baroness Andrews: Thank you. What you said about that part of it is significant because when you look at the five statutory principles, they are all about culture change, essentially. The statutory principles—“A person must be assumed to have capacity unless it is established that he lacks capacity ... is not to be treated as unable to make a decision ... because he makes an unwise decision ... best interests ... 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”—are very, very difficult. I know this is a difficult question, but do you think those statutory principles are being embedded in practice in culture?

Claire Crawley: I think they are in some places. Certainly we have seen evidence of individuals who previously would have had decisions made on their behalf. I shall give you an example. A woman in her very late 90s was diagnosed with vascular dementia. She was very frail and had no hearing, yet she was adamant that she wanted to live at home. Having a best interest assessment and a mental capacity assessment meant that she could make that decision and was able, with support, to go home. I think that is very different from where we were before the Act.

It is a huge culture change. Traditionally, social care and the health service have been a bit paternalistic in their attitudes towards patients and people using services. There is a huge thrust much more towards choice, control and self-determination. Front-line staff, such as care assistants and healthcare assistants, who are largely untrained and unqualified, probably need more assistance to understand the concept the Act is about. Perhaps particularly health professionals find the concept challenging. Social work traditionally has been about empowerment, change, choice and control, but clinicians sometimes find it difficult to feel that they cannot make a decision unencumbered by the patient’s view—but that is a terribly sweeping statement. We are getting there, but you are right: it is a fundamental change because it is a way of practising within human rights essentially, and it has got to be at the forefront of everything you do and all your practice. It is not an add-on.

Q3 Lord Patel of Bradford: I would just like to declare an interest: I am a former chairman of the Mental Health Act Commission, and I am currently a patron of a number of mental health charities. Carrying on from the question Baroness Andrews posed, you said that the Act has been used widely and it is understood fairly well in most quarters. Have you any figures about ethnic disparities in the use of the Act, lasting powers of attorney or the use of mental health advocates? Is that data monitored?

Claire Crawley: I am going to confess that I think it is monitored, but I am not sure. We could find out and come back to you, if that would be okay. My sense from the last IMCA report is that there is perhaps, as in many things, an underrepresentation of people from black and minority ethnic groups taking up IMCA services. That would probably be because of a lack of awareness of the service being available.

The Chairman: I think it would be helpful if we had a formal note on that.

Lord Patel of Bradford: Also on what is being done about that.

Baroness McIntosh of Hudnall: Can I just pick up the point you made about things that are yet to get bedded in and matters which have not yet worked out as originally anticipated? Is there currently any plan in government to look at the Act again with a view to amending it, or is it the view that it is just keeping on going until these things get bedded in? Are there any areas where amendment is thought to be necessary?

Nick Goodwin: I think overall the view is that there is no need fundamentally to amend the Act. However, you will be aware that last year there was some consultation around the Office of the Public Guardian and its ability to move to more digital services, and there is due to be further consultation on that very shortly. Within that, depending on what the final proposals are, there may well be some proposals for change around the lasting power of attorney provisions, but they are designed to facilitate the OPG to deal with lasting power of attorney in a way that customers want, rather than fundamentally to unpick what is behind the Act in respect of LPA. “Fairly limited at the moment” would be the answer.

John Hall: The feeling is that the fundamental framework and principles are sound, and that any changes that we need to make are around ensuring that implementation continues to improve.

Baroness McIntosh of Hudnall: So can I just follow that up? As far as the code of practice is concerned, you have all indicated that you think that it is regarded highly by users, but there are some issues that have arisen intermittently—in fact, more than intermittently—over the past couple of years. Is it your view that there is anything that needs to be done to look again at the code of practice, for example, to see whether that can be amended?

Nick Goodwin: We were scheduled to look at the code of practice about now to see whether it needs updating. Jonathan Djanogly, then the Minister with responsibility for this area, wrote to Alan Beith on the Justice Select Committee and said that the intention was to defer that so that we could look at the code of practice at the same time that we look at the OPG reforms, so it can be updated all at once. There is still a plan to look at it, but it is a little way in the future. That process would obviously be fairly comprehensive and would draw in observations from around government and around society.

Anne-Marie Hamilton: Similarly, in the Department of Health there are no plans to amend the legislation. On the code of practice for the deprivation of liberty safeguards, there are two cases before the Supreme Court in the autumn. They and the report of this Committee may suggest a need to amend the code of practice, for example. We will need to consider that in due course.

The Chairman: I appreciate that you are waiting for the decision of the Supreme Court. I think one of the cases is coming up in October. Obviously you perhaps want to be informed by the decision of this Committee, but once that information is available, can you give us any indication of when you would come up with a revised code of practice?

Anne-Marie Hamilton: No, we would need to discuss that with our Ministers.

The Chairman: I suppose that is something we could ask the Ministers.

Anne-Marie Hamilton: Yes.

Q4 Baroness Barker: We all know about the red tape challenge and scything through unnecessary regulation. A lot of the implementation of this Act rested on not just the code

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of practice but on a lot of regulation. Do you see anything coming out of the red tape challenge that is going to impact on current regulations under the Act?

Anne-Marie Hamilton: The red tape challenge was very helpful, and the comments we received are publicly available. There were comments on the Mental Capacity Act and the deprivation of liberty safeguards. Some were positive, some had concerns, particularly around the process for depriving someone of their liberty; for example, the forms involved in doing that. We are considering them, and we will need to decide how we respond in the light of what this Committee finds.

Baroness Barker: But it is likely that there is going to be change, rationalisation, a general move towards making it easier for individuals to engage with the legislation and secondary legislation.

Anne-Marie Hamilton: That is certainly what people called for in the red tape challenge. That again is something that we would want our Ministers to take a view on as we go forward.

Baroness Barker: It is not actually one of our questions today, but I wonder whether I might flag up to you that those of us who were involved in the pre-legislative scrutiny of the Act found that technical issues, digital issues, and the web did not really feature at all. I think they now do, and it is perhaps something that our Committee needs to reflect on. If that is part of the work you are doing, it may perhaps be helpful for you to inform us about that.

Q5 The Chairman: The United Nations convention on the Rights of Persons with Disabilities entered into force in May 2008, subsequent to the enactment of the Mental Capacity Act, and was ratified by the United Kingdom in June 2009. Have you considered whether the Act complies with the convention? What was the outcome of that consideration?

John Hall: We took legal advice at the time that the convention was made. The legal advice was that the Act was compliant. We understand that since then some concerns have been raised among some of the senior judiciary, and we have started discussions with them. To be doubly sure, we are doing a review this year to get further advice on that, but our view is that it is compliant.

The Chairman: You are carrying that out this year.

John Hall: That is right.

The Chairman: When do you expect that to be completed?

John Hall: By the end of the year.

The Chairman: Does that include addressing the suggestions from some quarters that the substituted decision-making is not compatible with Article 12?

John Hall: That is the nub of the review.

The Chairman: What about the research provisions in Sections 30 to 34 of the Act? Are you considering whether they are compatible with the prohibition on medical or scientific experimentation on persons with disabilities without their consent under Article 15?

John Hall: We are looking across the whole gamut of issues. This Committee's deliberations will be important to informing that.

Q6 Baroness Hollins: Before I ask my question, I should tell you that I am a retired consultant psychiatrist. I worked for 25 years as a consultant in learning disabilities services. I am also a family carer of a man with learning disabilities. I am a past president of the Royal College of Psychiatrists, and I am the current president of the British Medical Association. I want to ask you about implementation. There was initially to be a programme of work on implementation by the Department of Health, including local implementation networks. Can you describe for us the nature of your department's work on implementation and how significant the local implementation networks were and perhaps also whether your expectation was that the department would continue to lead on implementation or whether you saw a particular end point?

Claire Crawley: We did a massive amount of implementation of this legislation, probably more than is done on most legislation, because the fundamental challenge of the change of culture was recognised. It was originally planned to have a three-year programme to support the implementation. That was, in fact, extended to five years, so a significant amount of resource went into that. You are right that that was supported by nine local area leads as well as the central policy lead and local implementation networks were enabled and supported, and most of them are still going, I think. Obviously the role of the department is one of oversight and stewardship, but because we recognise that this is such a critical piece of legislation we are still involved in supporting implementation through commissioning. For example, we have commissioned SCIE to carry out work with care homes where it is important that people understand how the Act should work and what it does. We have supported SCIE to produce popular and very successful tools, including Social Work TV on SCIE TV, and we have worked with various professional bodies on a range of other guides, so in terms of implementation we have done a lot. I do not think we see the job as done; it is just what is appropriate and what levers we now have in this new system. The new Care Bill and the NHS reforms offer us an opportunity to refresh that work because we need to talk to people in the new NHS system about what responsibilities and accountabilities they have under this legislation.

Baroness Hollins: How well do you think the Act is known and understood by relevant professionals and others required to apply it, such as carers—you mentioned carers in residential settings—as well as individuals to whom it applies?

Claire Crawley: I think it is variable. I think it is growing. My main portfolio lead is adult safeguarding. I attend a number of events to speak, and we have hosted conferences about safeguarding, and mental capacity is always raised by professionals throughout those sessions, whether they are nurses, doctors, social workers, care home owners or inspectors. It is much bigger in the profession than it was, and the Care Bill is an opportunity to refresh and remind people of it. I think it is much less known, probably, among informal carers and family and friends, although all the information and data we are getting from the Office of the Public Guardian demonstrate that that is also growing—phenomenally, actually in terms of doubling and perhaps trebling. It is less important that people, like me as a carer or a family member, know the Act and the code of practice than that I should know what my and my family's rights are under the Act and how they can be protected and promoted. I think we are on a journey, but applications for IMCAs and LPAs show that there seems to have been a jump. There was a very slow start, as we might expect, but there has been quite a significant jump in awareness.

Baroness Hollins: I have a couple of supplementary questions. I want to pick up on something that you said about paid carers knowing more. An awful lot of carers have no or

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very limited training. Do you think that all carers working in services should have some training on mental capacity?

Claire Crawley: Absolutely.

Baroness Hollins: Is professional training on the Mental Capacity Act available through appropriate professional bodies? What has the department done to promote such training?

Claire Crawley: We have done work with what is now the College of Social Work and with the Social Care Institute for Excellence which is aimed at developing the training of professionals. We have commissioned a number of training programmes, tools and guides that are still out there and being used. As I said earlier, the department's view is that this is as fundamental to health and social care practice as any other legislation. Like the Human Rights Act, it has to be absolutely embedded in everyone's practice every day. It is not an add-on; it is not a specialist thing; it is not something you think about when suddenly you face a problem; it is there in all your work. That is a huge challenge.

Baroness Hollins: What about the royal colleges?

Claire Crawley: The royal colleges, particularly the Royal College of Psychiatrists, have all been very heavily involved in training their relevant membership groups. If you want more detail of that, I would have to go away and find out more.

The Chairman: Can we have a note on that as well?

Baroness Hollins: Just one final question: there are some dedicated roles, such as learning disability nurses. I think there were something like 30 learning disability liaison nurses working in acute hospitals. I gather the number is going down, and I think there is only one learning disability consultant nurse, but they have seen their role as working to support the application of the Mental Capacity Act within acute hospitals. Do you have a view within the department about their role in ensuring its application in hospitals and in community settings, where there are more learning disability nurses?

Claire Crawley: I think certainly they have a leadership role, but all employers and professionals have a personal, individual role as well. It would be an awful ask to ask so few people to somehow be responsible for that level of awareness. We find leaders in these posts who are absolutely committed to the principles and know how they pan out in practice.

Q7 Baroness Andrews: Can I just follow that up with two questions? The code says, "The responsible body should also have procedures, training and awareness programmes". Are you satisfied that all local authorities have those procedures and training? How do you actually know that? My other question follows from the post-legislative assessment that was made in October 2010, and we are two and a half years away from that. It is about NHS trusts. Again, it is an evidence question, because the assessment revealed an inconsistency in assessing capacity in some trusts to ensure that the Act was fully embedded. In 2010 it said that all such trusts have met the required conditions. How do we know?

Claire Crawley: In terms of hard evidence, could I sit here and say, "I absolutely know that every local authority has appropriate plans and training processes in place"? I could not say that because I have no way of getting that evidence. The regulator of the industry, as it were, the Care Quality Commission, does not monitor local authorities or inspect them any more, so I would not know. My understanding is that they are required to do that, and if

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they are not, they are not meeting their statutory responsibilities. What was the second question?

Baroness Andrews: The second question was slightly different and was about NHS trusts and their capacity to ensure that the Act is fully embedded. In 2010, they were finding trusts that had not achieved that, but they said by that point that they thought all trusts had. I wonder what sort of monitoring and evaluation had gone on for the trusts for them to have that assurance.

Claire Crawley: That would probably have been the CQC's process, as the regulator, rather than the department's process.

Lord Turnberg: To follow on from that, how switched on do you think NHS England and the clinical commissioning groups are to the Mental Capacity Act? Are you having conversations with them?

Claire Crawley: We are having conversations. They have got a massive agenda on, so trying to get into that conversation is a challenge for all policy areas, including this. We have a dedicated lead within our team who works on the Mental Capacity Act, and she spends an extraordinary amount of time tracking down the people to talk to, so we are making progress.

Anne-Marie Hamilton: Clinical commissioning groups already have clear responsibilities around the Mental Capacity Act, so that is part of what they are expected to do. NHS England is well aware that this legislation is part of its responsibility.

Claire Crawley: As part of the authorisation process for CCGs, they had to demonstrate that they had the right processes in place.

Lord Turnberg: Did they?

Claire Crawley: Yes.

Q8 Lord Faulks: Mrs Crawley, a great deal of care is provided by people who are not professional carers, by families and even friends. Are you satisfied that in so far as it is relevant the code of practice for the MCA is sufficiently communicated and understood by most or all them?

Anne-Marie Hamilton: I think there are excellent guides. For example, organisations such as Mencap, the National Family Carer Network and the Alzheimer's Society have a lot of materials that family carers can access to help them understand what they have access to through the Mental Capacity Act. The code of practice itself may not be in use by family carers, but there are other materials that are in use and are very helpful. For example, lasting power of attorney gets discussed on Radio 4's "Moneybox". It is part of the discussion for people to become aware of those rights, and it is leading people to ask for best interest assessments and to be more conscious of the framework within which the care is being provided.

Lord Swinfen: Do you have any system to identify families where informal care is being given by other members of the family so that help can be given to those informal carers, because very often they do not know what they are doing? They are just doing their best.

Anne-Marie Hamilton: No, I do not think we have a central system for identifying informal carers. There are so many people providing care of some sort or other to family or friends.

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I suspect that if they were looking for help or advice a lot of those people would look to organisations such as Age UK.

Lord Swinfen: General practitioners do not have any system?

Claire Crawley: No. We have been asking general practitioners for a number of years—at least 10, and probably more—to make sure they flag on patient records where carers are operating, to be able to offer them particular advice and assistance. Of course, we refreshed the carers strategy not long ago, and we do a lot of work with the various carers' groups on how we get information like this across. You are right that GPs are often the first point of call for most family carers and the place they go, so it is really important that GPs know the circumstances. Often, if they are family doctors, they will know the family and will have known it for some time.

Lord Swinfen: They should know the family; I am not sure they all do.

Claire Crawley: No, I appreciate that.

Lord Swinfen: Not under the modern system at any rate.

Q9 Lord Patel of Bradford: On the issue of training, have you any evidence or examples of what is happening in further and higher education in respect of Mental Capacity Act training? We have concentrated on the NHS, local authorities and existing professionals, but in terms of newly qualified practitioners, whether care assistants or social workers, is any influence being exerted to say that this needs to be a core part of what they are teaching?

Claire Crawley: I would be shocked if it was not, but that is not a sufficient answer. If you want more detail, again we would have to come back to you with it.

The Chairman: Could we have a written note on that? You speak about encouraging general practitioners to flag up the records so that people with capacity problems are identified. To what extent are records readily available to other care providers? The reason I ask that question is that I was, unfortunately, admitted to a hospital in Glasgow from court one day with an MI. I had had a previous one, but my records were in Edinburgh. They had to phone the consultant in Edinburgh—this is National Health Service, not private—to get details of the previous episode. Is that a problem in England and Wales? If a GP has flagged up that someone has this problem, would that be communicated to another agency which was dealing with his or her care? Before you answer the question, I should have declared an interest—not as a patient just now—as honorary president of a charity called Capability Scotland, which campaigns for and provides services for people with mental and physical disabilities.

Anne-Marie Hamilton: There is an awful lot of work around record sharing within the NHS and across the NHS and the care system and a programme of work around electronic record sharing, but I do not think either Claire or I is familiar with the details. We would be very happy to find out more for you and to send the Committee a note if that would be helpful.

The Chairman: The reason I ask that is that it is all very well to say that GPs should flag the record, but if not followed through and the people dealing with secondary care do not know—

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Claire Crawley: Particularly where people who may lack capacity are admitted to hospital in an emergency, that is a big issue.

The Chairman: They of all people might have even more problems than I did in communicating.

Claire Crawley: Absolutely.

Lord Swinfen: You say that GPs make a note on the patient's notes. That is all very well, but patient confidentiality may well mean that the GP cannot even to talk to close relatives. How do you get over that if someone with a mental incapacity could be in danger of endangering themselves and possibly other people?

Claire Crawley: Well, it is very clear that the GP in that case, if you are giving it as an example, has a professional duty of care to that individual and must share the information appropriately. It is recognised that they must do that. It is a delicate balance between confidentiality and sharing, but in the example you give, it is critical that they share information.

Q10 Baroness Browning: I had better declare my interests to begin with. I am a vice-president of the National Autistic Society and also of the Alzheimer's Society nationally. I am also the named carer of an adult relative living independently who has Asperger's syndrome. I want to ask you about independent mental capacity advocates. We have heard that the number has doubled in the past five years, but we also know from the report by Lucy Bonnerjea that it is very patchy. It seems to happen in some areas, but not others. Bearing in mind that the guidance to this Act says that an IMCA must—the "must" is in italics—be instructed and then consulted for people lacking capacity who have no one else to support them, can you explain why five years on this system is so patchy?

Claire Crawley: I think it is partly because the Act is not properly embedded yet and people's understanding is not as thorough as it needs to be. The fact that we have seen the numbers going up is positive, but they probably need to go up faster. One issue is that people often have friends or family who they prefer to use as their representatives. Our anxiety is that there may be particular cases, for example, in what is called adult safeguarding, where IMCAs should be involved and are not. Again, a lot of this is a question of awareness and time and building up the knowledge and understanding of when people need to be involved.

Baroness Browning: So when you see specific cases where this has not happened—for example, when your department received the Winterbourne View report; I have had the opportunity of speaking to the person who wrote that report and asked the question "Was the Mental Capacity Act used?", and it was not used or mentioned at all at Winterbourne View, where you may recall that some of the staff received prison sentences—what was your department's reaction when you identified immediately that that was where a weakness lay in terms of the implementation of this Act?

Claire Crawley: In terms of our response to Winterbourne View?

Baroness Browning: Not the response, but specifically in relation to the fact that Winterbourne View occurred without any reference to the Mental Capacity Act at all.

Claire Crawley: What happened at Winterbourne View shocked us all. In the wider context of what was going on there, in a sense one would have been surprised if they had understood and used the Act. Because of the abuse and the poor care, I do not think they

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had much understanding of any appropriate care or ways of working with people, if that makes sense. It was not the Mental Capacity Act alone that they had no awareness of. They did not have awareness of any proper working with those particular individuals, by the sound of it. For us, it was probably a salutary reminder that there are some people who are very vulnerable to abuse and exploitation who the Act should be protecting and is not, and we will have to do more about that more generally.

Baroness Browning: When you see something that I would describe as a trigger, who exactly in the Department of Health has responsibility for deciding that, yes, your department needs to do something about it?

Claire Crawley: I think ultimately it is probably Ministers.

Baroness Browning: Ministers? But presumably they would receive some sort of guidance from officials that it was time to act.

Claire Crawley: With Winterbourne View, they did not need any guidance from officials. The Ministers were very proactive in how concerned they were in wanting action to be taken.

Q11 Baroness Browning: Could I give you another example where the staff almost certainly would have been aware of the Mental Capacity Act? It is the reports that we have received over the years, the first from the charity Mencap, *Death by Indifference*, which involves the death of quite young learning disabled adults who are in acute hospital situations. They are not there because of their learning disability. There has been a supplementary report showing yet further deaths. In a hospital setting like that, you would expect all staff concerned to be up to speed with the Mental Capacity Act. What was your department's response to the reports from Mencap in terms of the Mental Capacity Act?

Claire Crawley: I do not feel able to answer that because that was probably led by my colleagues. I do not know whether Anne-Marie knows.

Anne-Marie Hamilton: Are you asking who the lead official is or what the reaction was in the department?

Baroness Browning: Not specifically. We have heard the word "embedded" used a lot this morning, and of course the objective must be to embed this legislation throughout the system, but when one comes across specific examples like that, which are complex, no doubt, quite clearly the Act is not doing what it is meant to do. Clearly, it is not embedded at all. What triggers a response to try to make it more effective? Who actually takes that responsibility in government?

Claire Crawley: I think that is the Minister, and you are right, guided by officials. That is one of the reasons why we are working so hard to ensure that we have proper conversations and outcomes with NHS England and CCGs because, in a sense, that is who we have to work through. The department is in the odd position that it has parliamentary responsibility, it is the steward of the system, it exerts leadership and it dictates the direction of travel, but it has very few levers at its disposal. We have, I think, very much got to build and work through the new bodies if we are talking about hospitals.

Baroness Browning: Could I just ask one more supplementary? It is really to the Ministry of Justice. I know you are waiting for the conclusion of court cases, but you have told us this morning that from your department's perspective, you are not of the view that this Act is in need of revision or review. When your department sees these quite high-profile

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cases—I have mentioned two, but they are by no means the only ones; there is unfortunately a steady progression of such cases—do you ever speak to the Department of Health about whether this legislation, on which both your departments rely, needs to be looked at seriously in terms of whether it is fit for purpose?

John Hall: We work together very closely. We have a number of forums and fora and working groups which we make sure we communicate. My team and the team that was formerly Nick's work very closely with Anne-Marie's team, so those conversations are happening in a joined-up fashion, if that is the question you are asking.

Baroness Browning: But the conclusion that your Minister came to based on those discussions and your advice was that there was no need to review it. Is that correct?

John Hall: Not a fundamental review at this point. That is where we are.

Baroness Browning: Does it not worry you somewhat because, although I know you are not the Department of Health, you must see these ongoing high-profile cases?

John Hall: I am not going to comment on interdepartmental relationships. We work very closely together, and the views that we take and the advice we give to our Ministers are very much joined up.

Q12 Baroness McIntosh of Hudnall: I think Lady Browning has sort of asked the question that I wanted to ask, but I want to take you back to the answer you gave on the question about the code of practice. Although I understood that you were saying that there are some court cases that still have to be resolved, I did not get a sense—I hope you will forgive me for putting it this way; I do not mean it impolitely—that there was a great deal of urgency in your approach to the possible revision of the code of practice, and that is exactly where the issues that Lady Browning has raised are likely to be impacted upon. I wonder whether you might like to give us a slightly refined answer to the question I asked you earlier.

Claire Crawley: I hope you will not think these are weaselly words from a civil servant, but the issue is that the code of practice is very good—most people say it is—as is the legislation. It is people putting it into practice that is such a challenge. We could review the code of practice and the Act and spend a lot of resources and time doing that and not make one jot of difference to people on the ground. Our energies are focused, I think rightly, on protecting individuals rather than on revising the code. If the code was followed, those dreadful things would not happen. That is what we struggle with. What are our levers? What is our ability? How do we work with the regulator, in particular, to make sure that a good code of practice and some very good legislation actually happens?

Baroness McIntosh of Hudnall: Fair enough.

Baroness Andrews: Given that the system is changing and that the CCG is in place and so on and so forth, is there any opportunity or reason to look again at measures of evaluation and impact? That is what we are grasping at here. You have just identified it so coherently.

Anne-Marie Hamilton: I think you are right. In terms of the department's role going forward, we want to work with our system partners, such as the Care Quality Commission, NHS England and others, in understanding what is happening out there and the levers that we have to effect change. Part of that should certainly be evaluating and understanding what is happening and what evidence, qualitative and quantitative, we have to inform that. To respond to the earlier point, we take that forward by working with those system partners.

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The response to Winterbourne View was led across the social care and NHS sectors and across the whole department with the different teams coming together to work on it. You are right that going forward we need to evaluate and understand.

Claire Crawley: We are working with colleagues within the department on what measures will be used to evaluate the performance of NHS England delivering on the mandate. There is some work going on on a range of issues, and we are trying to work with it on safeguarding and the MCA.

The Chairman: Can you give us a detailed note on that?

Anne-Marie Hamilton: Yes.

Q13 Baroness Hollins: I want to pick up something that you said in response to Baroness Andrews at the beginning about the principles of the Mental Capacity Act. Baroness Browning asked about Winterbourne View hospital. You said at the beginning that practice is now based on human rights, although untrained staff may not understand what that means. At Winterbourne View, they were mainly trained staff, but you said it was not an issue to do with the Mental Capacity Act. I appreciate that it was criminality really, but it was also to do with the lack of respect that those staff were showing to the patients, because it was a hospital. There is a really important issue about how far the evaluation of existing facilities looks at human rights approaches. Is there anything in the evaluations of services that are taking place that might be able to highlight a lack of a human rights approach?

Claire Crawley: Actually, that question is very timely for me, because I spent two hours yesterday with the Care Quality Commission talking about just these issues. How could Winterbourne View happen when the regulator was going in, GPs were going in and the local authority was commissioning places? You would have thought that somewhere in the system—it seems almost a complete failure, does it not? I was having exactly those discussions about how the CQC is going to train its inspectors, because perhaps the inspectors are not looking for the right things, and how they talk to people using the services, very much around the points you made. It is not just the staff delivering the service who have to have this approach, it is also the people who are monitoring and regulating them. Winterbourne View was just a dehumanising regime, was it not? It just seemed to be a catalogue of failures.

Baroness Hollins: Are you confident that the Care Quality Commission has got this kind of inspection in hand?

Claire Crawley: I am absolutely confident that it is working on getting it in hand. It sets great store by that work.

Q14 Lord Patel of Bradford: You said early on that the Mental Capacity Act is not an add-on. You are right in that. However, many practitioners have described the deprivation of liberty safeguards as an add-on to the Mental Capacity Act with a very different and less empowering ethos. Do you agree with that? If you do, what implications has it got for the Mental Capacity Act and its implementation?

Claire Crawley: I do not agree with that, and it is not the Government's view. You are absolutely correct to say that they came later. The Act was amended through the Mental Health Act, and one of the reasons for that was that until Bournemouth, which was the high-profile case that brought this all to light and to the fore, there was not really an understanding of the position that people were finding themselves in in care homes and

hospitals. Certainly some Members of the Committee will remember that before the Mental Capacity Act got Royal Assent, it did not focus on it particularly. I think they are empowering. Partly it is the way they are misinterpreted or misunderstood. The language does not help. People concentrate on saying "deprivation of liberty" when what they should be concentrating on is the word "safeguards". These are about making sure that people who in their best interest have some restrictions on their liberty—minimal restrictions—to keep them safe have adequate recourse and protection within the law and within the system.¹ I very much see them as empowering because we see a range of people whose treatment is being challenged, including through the Supreme Court and the Court of Protection work. No, I do not accept that. I accept that the very terminology might feel confusing and inappropriate, but the ethos is to allow people to make as many decisions as they can and to be as free as they can.

Lord Patel of Bradford: Have you seen any discrepancies in terms of people understanding whether they should use the Mental Health Act or the Mental Capacity Act? Many would be almost de facto detained in these care homes.

Claire Crawley: Winterbourne View was an example. Nobody seemed to know about the Mental Capacity Act. I do not think there is confusion in the law, but people do not always understand which legislation they should be operating, and often it should be the Mental Capacity Act. We are working with colleagues on the mental health policy area to try to pull that apart, yet make it a coherent whole for people. We are doing some work on that.

Lord Patel of Bradford: Is that something that the Care Quality Commission's mental health arm should be homing in on?

Claire Crawley: The person who leads on the Mental Health Act—a very senior member of staff—also leads on the Mental Capacity Act, so that is one way of bringing that together.

The Chairman: I think we need to move on to Question 8.

Q15 Lord Swinfen: You have just been talking about deprivation of liberty. Are the standards being operated the same throughout the whole country? If not, what is being done to bring the lowest standards up to the highest standards?

Anne-Marie Hamilton: I think everybody operating the deprivation of liberty safeguards is using the same safeguards, but there are regional variations in terms of the number of authorisations being applied for. We can see regional variations in the extent to which the safeguards are being used. The Care Quality Commission's annual report flags that. We are discussing with the Care Quality Commission what it might do. When the original implementation programme happened, regional managers spent a lot of time going up and down the country talking to areas about how to raise awareness and how to get smaller providers familiar with this. There was an awful lot of work done. It is probably inevitable that there will be regional variations because the population make-up differs across the country. Some areas have higher populations of older people, some areas have more hospitals and more care homes and some care homes have higher populations of people with dementia. Variation is inevitable in terms of the number of safeguarding authorisations

¹ Correction subsequently provided by the Department of Health: this sentence should refer to the Deprivation of Liberty Safeguards applying to people who have been deprived of their liberty, rather than people whose liberty has been restricted. A deprivation of liberty can only be authorised when it is in the person's best interests and is the least restrictive (and therefore a proportionate) means to ensure the person receives the care and treatment they need.

that you see, but we think that there is also something within that that means that it is not being implemented uniformly across the country and that some areas are doing this better than others.

Lord Swinfen: Your office could be learning lessons while looking at this. What are you doing to make certain that the lessons you learn to improve standards are promulgated throughout the country?

Anne-Marie Hamilton: That is something that the Care Quality Commission, as the regulator, talks about in its annual report, stating the issues it has identified and how it might build them into its processes going forward.

Lord Swinfen: Reports are very good, but they very often lie on the shelf. What are you actually doing to make certain that the recommendations are implemented?

Anne-Marie Hamilton: In terms of the Department of Health's role? It is the role of the regulator to share that. The Department of Health continues to fund best practice guidance through the Social Care Institute for Excellence. We continue to try to raise awareness through the work that we commissioned from SCIE. We play the role that we described earlier in bringing together the different system partners, including NHS England, whose responsibility is to address this throughout the NHS. Local authorities have a statutory obligation to have this locally.

Q16 Baroness Barker: Lasting power of attorney is perhaps the part of this legislation that impacts on the general public first and most directly and is therefore very important. You said that there had been 750,000 LPAs. Can you tell us the time period for that? How does that compare to enduring power of attorney rates before the Act? Is the rate as high as we would have anticipated when the legislation went through?

Nick Goodwin: The actual figure is slightly under 750,000. LPAs have been registered since October 2007. That is about 20,000 a month at current volumes. It is very difficult to compare that with the previous system of EPAs. There is a lot of public information on the volumes, but I can give more on that.

Baroness Barker: I think we would like a lot more detail on not just when they are registered but when they are activated. We would like to know from different practitioners, such as people in memory clinics, how they are panning out with people and their families. At the time the legislation went through, there was considerable concern that the cost would be off-putting to people. We would like to have whatever data you have on that. If we can have a pretty full report on that, that would be helpful.

Also, advance decisions were a very important part of this legislation. They were controversial when they came in, but I think some people have changed their mind. What data do you have on the use of advance decisions?

Claire Crawley: I think the honest answer is that we do not collect that data. I am sorry; that is not satisfactory from your point of view, but I do not think we do.

Baroness Barker: Does anybody in the course of their professional duties?

Claire Crawley: Not that I am aware of.

Lord Swinfen: What about the solicitor who draws up the lasting power of attorney? Do they have to register it anywhere?

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Claire Crawley: The lasting power of attorney is registered with the Office of the Public Guardian.

Lord Swinfen: It should be able to produce the answer for you.

Claire Crawley: Advance decisions are different from LPAs.

Lord Swinfen: All right, but the modern one, does that have to be registered anywhere?

Claire Crawley: The lasting power of attorney has to be registered with the Office of the Public Guardian, which may have data. Advance decisions can be just written by an individual on a piece of paper and signed, so they are not registered anywhere.

Lord Swinfen: They just get put in a drawer and when the time comes no one can find them.

Baroness Barker: The intention was that they would be part of a patient's record and available to practitioners at the time of treatment. For example, if somebody had a fluctuating mental health condition, they could say, at a period when they had capacity, "I know from experience that when I lack capacity I may make certain unwise decisions. If I do that, I wish you to ignore what I say at that point". The anecdotal feedback from a number of practitioners is that they have been helpful. It is a great shame that there has been no systematic look at their effect across the NHS.

Claire Crawley: Yes, I can see that. One of the reasons why the inquiry is going to be so helpful for us is in getting that different perspective of what is useful and what is not. Like all public bodies, we have restrictions about overwhelming the system with so much data collection that it cannot get on and do its job, but I understand the point you are making, and it is very interesting.

Q17 Baroness Andrews: May I pursue that, Lord Chair? At paragraph 9.38, the code of practice clearly analyses the complications that arise about the business of logging an advance decision and in determining whether it even exists: "It is the responsibility of the person making the advance decision to make sure their decision will be drawn to the attention of healthcare professionals". We are dealing with people in intermittent states of confusion, very often. When you come to look at the code of practice again and the evaluation methods, it might well be worth looking to see, on the basis of what experience you can collect, whether there is something that can be done to tighten this up. This was such an important—it is increasingly important—issue for self-determination.

That was not going to be my question. This is my question. I have personally gone through the process of LPA, and it is not easy. I know that you tried to simplify it, but the terminology is still very complex and unusual, and the form is very long. Someone described it to me as being like reading a Russian novel because by the time you are halfway through, you have forgotten whether you are the donor or the attorney. Is there some way in anticipation that you can have another go at that?

Nick Goodwin: Yes.

Baroness Andrews: Good.

Nick Goodwin: It is a very common criticism. That is what the OPG is trying to simplify. We anticipate that in a short number of weeks, we will have made the first step on that. It will be a bit of a journey to get there. The first step will be a new online tool that will mean

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that, if you have gone through that laborious process of filling in all the information, the form is not sent back to you because you have got a few bits in the wrong box,

Baroness Andrews: That is exactly what has happened. They come back to you with another charge because you have the terminology wrong, which is causing a bit of aggro. It might be worth taking evidence from somebody who is aggrieved.

Nick Goodwin: Again, there has been consultation on this. The aim is to make it much more user-friendly and to improve the process in the Office of the Public Guardian. There have already been some improvements. We have reduced the statutory waiting time and there are some minor amendments intended to improve customer service. At the same time that the online tool comes in in a few weeks' time, there will be further detail. There were some issues that we consulted on last time that we needed to refine a bit. To get fully digital by 2015, for example, would probably require some primary legislation. There will be more detail on that very shortly. Certainly we are with you in terms of the frustrations and improving the user experience.

The Chairman: When those details are available, can you make them available to the Committee?

John Hall: I understand that you are going to be questioning the Public Guardian. He will be able to give you a lot more of this information.

The Chairman: I think we will go to courts and regulation because Lord Faulks has to leave early. I should also say that that our adviser has to leave early to attend a funeral, so it is no disrespect if either or both of them walk out in the middle of your evidence.

Q18 Lord Faulks: Thank you, Lord Chair. I should have declared an interest earlier in that I am a practising barrister and from time to time I act on behalf of those who lack mental capacity and for doctors and healthcare professionals in cases where mental capacity is sometimes an issue. I want to ask you about the Court of Protection, which was set up, or at least expanded in its scope, by the Mental Capacity Act as a single integrated framework, as recommended by the Law Commission. In general terms, are you satisfied that it is being effective?

John Hall: The Court of Protection was bringing together those things for the first time. It was one of the big challenges of implementing the Mental Capacity Act. It has been a slow journey with some hiccups along the way, but we are very much getting there. In terms of case load, the emphasis is still on finance issues rather than health and welfare issues, which is what you would expect. We have made some changes and amendments along the way, particularly in terms of moving the administration from the Office of the Public Guardian to HMCTS to make things run a bit more smoothly from the court's perspective. There was an anomaly in the Act which meant that no deputy judges were able to sit, and that created a bit of a backlog, but we have made some amendments to the Act to circumvent that. We think we are heading in the right direction, but there is still more work to do.

Lord Faulks: I see that actually the Act says: "The court may sit at any place in England and Wales, on any day and at any time". In practice, are there a lot of delays? You have just described some of the improvements. Do you think it is responding quickly enough in general terms?

John Hall: There have been problems with backlog, but again that is getting better. The change around moving the administration from the Office of the Public Guardian to HMCTS

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has improved that because of buildings. Even though the court is a separate jurisdiction, it can sit anywhere within HMCTS's estate, so that has definitely got better. We now have regional sittings as well as sittings in London, so people do not have to travel all the way to London to have their hearings.

Lord Faulks: There have been some changes brought about by the LASPO Act and there is now a consultation on changes to legal aid. Have any of those changes had an impact on the availability of legal aid and therefore impeded in any way access to the Court of Protection?

John Hall: As far as I understand it there have been no changes in the way that legal aid is available for cases in the Court of Protection as a result of either of the two reforms.

Lord Faulks: You just described changes to the Office of the Public Guardian and the potential impact on the MCA. Is there anything you want to add?

Nick Goodwin: Sorry, could you repeat that?

Lord Faulks: What impact do you think that changes in the Office of the Public Guardian will have, if any, on the application of the MCA?

John Hall: We hope that they will improve the application of the MCA. The volumes, particularly of lasting power of attorney, have been increasing, but there is clearly a lot more to do. The Office of the Public Guardian has taken a kind of gentle approach to publicising the need for everyone to get a lasting power of attorney. Its concern—which is right—is that it did not want the office to be overwhelmed with more applications than it can handle. There is a twin-track approach of gradually raising awareness and expectations and improving the infrastructure. Digital delivery will be a key part of that. As the system becomes more robust and more able to handle the capacity, communications and awareness-raising will increase at a similar rate.

Lord Faulks: There was a recent, highly publicised case of someone being sent to prison by the Court of Protection. That hearing was not carried out in public in the way that you would normally expect a hearing to take place. I think there has been criticism of that. Can you reassure us that that will not happen again?

John Hall: You would not expect me, I am sure, to comment on individual sentencing decisions.

Lord Faulks: No, but as a matter of principle.

John Hall: As a matter of principle, the president has given guidance saying that all contempt proceedings in the Court of Protection should be heard in open court. More broadly, I know there have been concerns around transparency and openness in the Court of Protection and in the family courts. Ministers had already asked the president of the Family Division to do a review and assessment of what changes might be needed for the family courts. The Secretary of State has also written to him to ask him to look at the Court of Protection alongside that work and will be discussing the president's proposals with him shortly.

Lord Faulks: Would it be fair to say that that was an exceptional case?

John Hall: It is the only case we are aware of at the moment where someone has been imprisoned.

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Lord Faulks: Are you satisfied that the regulatory framework is robust enough? There are a number of different regulators, effectively, although, as I understand it, the CQC is responsible for the quality of care. The Care Bill currently going through Parliament proposes new powers. Are you satisfied that the regulatory framework is sufficiently robust?

John Hall: That is not my department.

Anne-Marie Hamilton: The regulatory framework has a number of parts. Obviously, the Court of Protection plays an important role in challenging decisions. Independent mental capacity advocates are also an important part of it, as is the role of the relevant person's representative in the deprivation of liberty safeguards in being able to request a review. As you say, the Care Quality Commission as the regulator also has a key role in monitoring compliance. It takes that role very seriously and is looking at what more it can do to enhance it further. The Care Bill adds to its regulatory tools for that.

Lord Faulks: Do you think the Court of Protection needs any additional powers?

John Hall: Not at present that we are aware of, but there is a very new president of the Family Division. He is also president of the Court of Protection and he will take a view in the discussions.

Q19 Baroness McIntosh of Hudnall: Lady Browning has had to leave, unfortunately, or she would have taken you back towards the area which she raised with you earlier in the discussions: broadly what one might call the culture of care and the lessons that you might have learned from the high-profile cases. We have already touched on some of that. Can you say what the most significant findings were as far as your departments were concerned as regards the care being given to people who lack capacity? Can you reflect on a matter that probably exercises quite a lot of people, which is that at the level of implementation, which you rightly identified as being the real difficulty, we are looking at a large number of people giving care who are probably undertrained and certainly underpaid by any standards, given the sensitive nature of the care that they are delivering? Can you indicate in what way you are able from the departmental position to influence the private sector providers in getting them to think about their cost base and where they should appropriately be putting resources?

Anne-Marie Hamilton: In answer to the first part about what we can learn from Winterbourne View and other instances, there are specific issues around the management culture within those organisations focusing on, for example, financial targets rather than the care of the people they are caring for and not focusing enough on taking account of an individual's best interest and putting the person at the heart of the decisions being made about their care. In Winterbourne View, the care planning was poor and little attention was being paid to what family and friends were saying and what the individual users wanted. Obviously there were a lot of out-of-area care placements within Winterbourne View which were not being reviewed and the person was not being put at the centre of the decisions being made about them.

In terms of the low-paid workforce, obviously there are legal requirements around the minimum wage. Our Minister has been calling attention to that a lot recently for private providers. They are under a duty to meet those requirements.

Baroness McIntosh of Hudnall: I just want to pick you up on that. The minimum wage is very low—we all have to recognise that—and the kind of care that is being delivered is of an

extremely personal and sensitive nature. Is it appropriate that the standard that should be applied to care providers is that they employ people at the minimum wage?

Claire Crawley: No, it is not. I wanted to come back more generally, although I will not lose sight of that problem. The issue that Baroness Hollins raised earlier was that, interestingly enough, Winterbourne View was staffed by qualified staff; it was not the lowest paid or the poorest trained, and we need to think about how that could be the case. In the statement the Government made, they said that fees for services should reflect the true costs that providers have to pay. It is a hugely challenging environment for care providers. I do not think there is no relationship between low wages and poor quality, but there are other people earning that money who are delivering brilliant care.

There is something else as well as money, and I think you would agree that lots of people do not just do it for the money. They could go elsewhere such as Sainsbury's—poor old Sainsbury's always gets this. It is more complicated than “Cheap, bad; expensive, good”. There is something about culture—I am sorry to keep using that word. It is that culture and attitude and whether we care for the staff in other ways as well as in monetary ways. Do we give them a career path? Do we acknowledge that it is hard work? It is really hard work. I have worked in residential care with some very challenging individuals—and that was just the staff. It is really hard work. Physically it can be quite hard, but emotionally it is incredibly draining and demanding. I do not know that we have really got the culture within our health and social care sector to know how to support that bit of staff. How do we support the person who has had a dreadful day on the ward, or who feels dreadful that they are running around and know that they should be stopping to feed someone, or know that Mrs M just wants someone to sit and talk to her and is terribly depressed and isolated? It is a huge issue. We are aware of it. We are struggling about how we respond, but one of the big things that has come out of Francis is all this talk about compassion and care, and that has to be for the workforce as well. If you have an uncared-for workforce, they cannot deliver good care.

Q20 Baroness Barker: In the high-profile cases we have had, what was the role of the safeguarding vulnerable adults boards? Where were they when all this was going on?

Claire Crawley: Are you talking about the social workers doing safeguarding investigations or vetting and barring, or both?

Baroness Barker: We have had the safeguarding vulnerable adults boards for some time, and the legislation is about to change and put them on a different footing. Following your previous answer, how do we make sure that they do not just have the task but have the ability to make it happen? Secondly, most people who have a relative with a mental health condition know that there is mental health legislation. They may not know what it is, but if something goes wrong, they know there is legislation. Is the fact that most relatives are completely unaware of the Mental Capacity Act a significant factor in bad practice not being challenged?

Claire Crawley: Ooh, there is a lot in there. I shall start with the boards. They are going to be made statutory and to have statutory membership and statutory functions including some more transparency about what they do and about listening to the community and what it wants them to do. Where were they in Winterbourne View? Nowhere to be seen, it seems. One of the things that struck me very forcibly on reading the serious case review that Baroness Browning referred to earlier was that a number of people turned up at the local Accident and Emergency department from Winterbourne View—all from the same place, if not the same individuals—with really quite severe injuries, such as missing front

teeth, dislocated collarbones and lacerations, and the A&E staff accepted the staff's word that it was because members of staff had had to defend themselves. In a sense, the whole system has to be much more vigilant and aware because I do not imagine the board knew about that until the serious case review. There is something about being able to spot abuse. The police also took the staff's word for granted. Having the police, the NHS and local authorities as core members of these statutory boards and giving them much clearer functions and powers under the law will make a difference, but it is not a replacement for vigilance, awareness and understanding. I am sorry; I have forgotten the second part of your question.

Baroness Barker: It was about relatives' and carers' knowledge of the Act.

Claire Crawley: I used to be of the view that knowledge of the Act, a bit like the Mental Health Act, is not so important as long as you know your rights, but my view has changed about that because people feel much more confident in saying, "Actually, this is my entitlement; you have to do this". This is the work we have tried to do. We are working more with partner organisations because the department has a critical view, but it is a bit like the Government's role with the Human Rights Act. It can do so much, and should support and promote it, but we need every partner in the system to do their part. We need CQC, the local authority and the NHS to play their full part. They are contributors; they are not passive recipients of what the Government do. They have a role in this system. We have a role in ensuring that they carry that role out. Your point about relatives and carers is really interesting because we keep talking about raising expectations and the rising expectations of people who want more from the system and know their rights. Maybe in this case that is not true and maybe we need to reflect on that. When you have much more evidence as a Committee, it will be interesting for us to see our way through that.

Q21 Lord Turnberg: You made an impassioned plea for better care for staff, quite rightly. Do you think that the Care Quality Commission has a role when it makes its inspections in ensuring that the staff are supported?

Claire Crawley: That was very much part of the conversation I was having with CQC yesterday, saying that care does not happen in a vacuum, we have to recognise that this is a very tough job and asking what is its role and its inspectors' role in supporting improvement in practice and care and looking after staff as well as the people using the service, as well as telling them what they are not doing right. There is something about. Hopefully, we are all in this business for the same reason: to improve the lives of people, to make a good impact. We need to work much more collaboratively to do that and to understand each other. I think there have been too many adversarial relationships between providers and local authorities and between providers and the regulator. We need to work together positively to improve care.

Lord Turnberg: Are the regulators perceived as being inspectors with a severe visage or are they regarded as friends to make sure that things are happening correctly?

Claire Crawley: I think the former, largely.

Lord Turnberg: That is not very helpful for supporting the staff.

Claire Crawley: No. Some areas are building on that. Some CQC teams are doing some of that work, but we have really good examples of local authorities or what were PCTs having, for example, small clinical support teams who will go into a nursing home that is struggling with some of the care and help it to build up its standards. That is the approach that we

want. This is not about driving people out of business but about keeping people in business and improving their services.

Anne-Marie Hamilton: The Care Quality Commission works alongside other bodies within the system. We mentioned the Social Care Institute for Excellence, and there are similar bodies on the NHS side that have a specific improvement function in terms of working with providers in the sector.

Lord Patel of Bradford: Just a quick point in respect of the inspectors: I suppose one should recognise that the mental health inspectors of the Care Quality Commission were the old commissioners, who were visitorial members and not inspectors. So one thing there is that their role was never to inspect and always to visit and interview detained patients. That is one element where all the evidence, or a majority of the evidence, was gleaned from actually talking to patients and not from other inspection tools. For me, a lot of Winterbourne View would be tackled if we honed in on that visitorial talking to patients.

Anne-Marie Hamilton: The Care Quality Commission piloted a study in 2011-12 around how they could try to understand more from what the users think in terms of the deprivation of liberty safeguards. I think they plan to learn from that in terms of how they can make that a bigger part of their role going forward, because I think they recognise and would agree with what you said.

Claire Crawley: This has obviously given the CQC quite a shake-up, all this. I know they have recognised, for example, the need to return to specialism inspection. It is a big ask of a generalist sometimes to understand all the various types of provision that are being regulated, and they are really looking at their methodology—you know, how do you get actual evidence from people and much better training for their own staff, because actually the quality of an inspection in a sense is only as good as the quality of your inspectors.

Q22 Lord Swinfen: Has practice under the Mental Capacity Act led to greater or less involvement of carers and families in decision-making? Have there been tensions between involvement of carers in decision-making and the aims of autonomy? If so, what have these been?

Anne-Marie Hamilton: I think we would say yes, it has led to greater involvement of families, as we understand it, in terms of the best interest assessment and the family and friends and carers of people being consulted as part of that decision-making process. I think there are bound to be tensions, and I am sure there have always been tensions between family views and the views of the person involved. The best interest assessments puts a process in place to discuss those views and reach a decision, hopefully as far as possible that the person themselves wants, respecting their capacity to make that decision. It may well be that some family members are not so happy with that outcome, but I think those tensions have probably always been there. The Mental Capacity Act puts a framework in place to enable a decision to be made in the individual's best interests.

Q23 Lord Alderdice: The question that I would like to put to you is whether you are satisfied that the relationship between the Mental Capacity Act and mental health legislation is really fully and properly understood, and whether there are any difficulties that arise amongst practitioners, particularly where there is medical work involved. I draw attention to the fact that I am a retired consultant psychiatrist from Northern Ireland, and have involvement in a number of mental health charities.

That leads on to the second part of my question, which is of course that in Northern Ireland we have had the Bamford review some years ago, which recommended a more unified

framework across mental health and mental capacity. It has not been implemented yet; the department of health took the lead on that, and I think there has been a little bit of hold-up in bringing along the Department of Justice in Northern Ireland, despite the fact that the Minister is a former social worker and very keen to see it happening. I wonder if you could perhaps help us understand if you do see any dilemma between the two, and if you think that a more unified approach would be helpful in addressing any problems that might be arising.

Anne-Marie Hamilton: The relationship between the Mental Health Act and the Mental Capacity Act is clear in law, but I think you are right that in practice it is not always understood by professionals using it. There are probably particular issues around people detained under the Mental Health Act and whether or not the Mental Capacity Act could be used in those circumstances. Professionals understand and are aware of both, but probably in reality there is confusion about how the two are used in practice. That may reflect the fact that the Mental Health Act has obviously been in existence for considerably longer than the Mental Capacity Act, so it may be a question of time and experience and practice, as people get more familiar with both pieces of legislation. In terms of whether or not it would make sense to bring them into a unifying piece of legislation, I suppose in a sense that they have a different ethos and approach and are clear in law. I am not sure whether that would add value, but it is not something we have discussed with our Ministers, for example.

Claire Crawley: We have commissioned some research about this, because we are aware that it is an issue for people, and we have only recently received that so will need to look at that research and what it says. But one of the things it does say quite clearly, I think, is that within psychiatric mental health settings there is poor understanding of the Mental Capacity Act, so we will need to look at that—and look at it jointly with our colleagues in mental health.

Lord Alderdice: You have suggested that one of the reasons might be just because the mental health legislation has been around for longer. Are there any other reasons why it might not be clear in people's minds, as practitioners?

Anne-Marie Hamilton: I think the research that we received, which we would be happy to send to you and which reported this year, did particularly identify it as an issue within the hospital settings. Maybe that is because people are more familiar with using the Mental Health Act, which I suppose relates to what I said about use and custom. It suggested as well that there might be issues around the complexity of the process that people need to adhere to for the deprivation of liberty safeguards, and that that might also be something that people were experiencing. So it may well be not only understanding of it, but also “How do you use that piece of legislation in practice?”.

Lord Alderdice: Lord Chairman, I would certainly be interested in taking up the offer of sight of the research work. That would be very helpful. Could I just be clear whether there has been any discussion with the department of health and social services and the Department of Justice in Northern Ireland about their approach to Bamford and implementation?

Claire Crawley: I am unaware of that.

Anne-Marie Hamilton: I am, similarly.

Claire Crawley: It might be that we could go back and ask colleagues.

Lord Alderdice: I would find that very helpful.

John Hall, Nick Goodwin, Anne-Marie Hamilton and Claire Crawley – Oral Evidence (QQ 1-24)

Claire Crawley: Okay. We will do that.

The Chairman: Again, just a note confirming one way or another.

Q24 Lord Faulks: If you could help me, I wonder if you could just give us an example of where there is a potential tension between the two different Acts—a concrete example.

Claire Crawley: In law or in practice?

Lord Faulks: In practice.

Claire Crawley: It is difficult to use Winterbourne View as an example, because so much was wrong at Winterbourne View, but clearly there were people there who should have been treated under the Mental Capacity Act and were not. They were detained under the Mental Health Act—if they were detained at all, actually, because I have sense that some were probably illegally detained, because they were neither detained under the Mental Health Act or the Mental Capacity Act. So in sense, although it is an extreme example, I am sure in lesser severity that is mirrored around the country, I would have thought; it cannot be the only one.

Lord Patel of Bradford: Just on that, if any of the patients were detained under the Mental Health Act, then there is potential for a second opinion. Now, that is a big issue if people are almost de facto detained using the Mental Capacity Act, but there is nobody else coming in.

Claire Crawley: They have to be reviewed under DOLS—

Lord Patel of Bradford: By the local authority.

Claire Crawley: Yes. They have to be reviewed, and also people can apply to the Court of Protection and challenge that detention.

Anne-Marie Hamilton: Everybody deprived of their liberty through the deprivation of liberty safeguards has a relevant person's representative. They may also have an independent mental capacity advocate. Those people can request a review at any point in the process. So if that is working properly for someone, they can request a review of the deprivation of liberty. Then, as my colleague said, after a year it would be reviewed anyway, because the deprivation could not be for longer than a year without review.

Lord Patel of Bradford: All the more reasons the CQC mental health people need to get back to specialisms, understanding the difference between the two laws, I think.

Lord Swinfen: Are the local authorities very often not the people running the care homes or responsible for them, so in actual fact they are reviewing themselves?

Claire Crawley: No, local authorities very rarely run care homes these days. The vast majority are in the independent sector.

Lord Swinfen: Yes, but I know that some of them are still run by local authorities.

Claire Crawley: Very, very, very few.

Anne-Marie Hamilton: And I think the Mental Capacity Act and deprivation of liberty best interest assessors have to be separate from the local authority, so that there is not that conflict of interest in those cases where that is the case.

John Hall, Nick Goodwin, Anne-Marie Hamilton and Claire Crawley – Oral Evidence (QQ 1-24)

Claire Crawley: I think perhaps the biggest challenge is one professional challenging another's judgment and decision, and I am sure that is true in most professions.

The Chairman: Lord Turnberg, a final question?

Lord Turnberg: I think my questions about the CQC have been asked; we have dealt with those.

The Chairman: Well, thank you very much to all of the witnesses for the marathon. You have lasted very well, and I hope you get a well deserved lunch or something from the departments.

Claire Crawley: I do not think so.

The Chairman: Thank you very much.

Baroness Barker: Lord Chairman, I completely forgot to declare my interests. I got stuck straight into the questions, so can I refer people to them in the list?

**Ms Nicola Mackintosh, Ms Katie Johnston, Professor Richard Jones
and Ms Kirsty Keywood – Oral Evidence (QQ 25-44)**

Evidence Session No. 2

Heard in Public

Questions 25 - 44

TUESDAY 25 JUNE 2013

Members present

Lord Hardie (Chairman)
Baroness Barker
Baroness Browning
Lord Faulks
Baroness McIntosh of Hudnall
Lord Patel of Bradford
Baroness Shephard of Northwold
Lord Swinfen
Lord Turnberg

Witnesses

Ms Nicola Mackintosh, The Law Society, **Ms Katie Johnston**, Policy Officer, Liberty, **Professor Richard Jones**, Honorary Visiting Professor, Cardiff Law School, and **Ms Kirsty Keywood**, Senior Lecturer, University of Manchester

Q25 The Chairman: Good morning. Welcome to this session of the Select Committee on the Mental Capacity Act. We are grateful to each of you for attending to give evidence this morning. I should make you aware that the evidence session is webcast as well as transcribed, and that it will be possible for witnesses to correct the transcript if there are minor errors—although obviously you cannot change your evidence. I understand that Professor Jones wishes to make a brief opening statement.

Professor Richard Jones: Thank you very much, Lord Chair: it will be brief. I thought it would be helpful if I indicated some of the issues that have occurred in my practice. The Committee may wish to ask me questions about them later. I must explain that my practice does not include advice on the financial aspects of the Mental Capacity Act. My experience is limited in that respect. I thought it might be helpful to look at the Act itself and then at DOLS, because although the DOLS legislation is part of the Mental Capacity Act, in practice they are two separate pieces of legislation. That is how they are regarded. I have three brief comments on the Act itself.

First, it is generally well drafted and easy to understand. In my experience a major problem is that many people who should be aware of the Act are not, and those who are aware of

the Act often have a flawed understanding of its provisions. In that respect I take issue with the evidence that this Committee received last week from officials who indicated that the Act was well embedded in our culture. My experience, and, in my opinion, most of the evidence, points in the opposite direction. The Act is not well embedded in our culture. There is a lot of work that needs to be done. My second point relates to what in my opinion are unrealistic expectations that the Act places on both lay and professional carers, in terms of capacity assessments and best-interest judgments. I think that those expectations lead to the major provisions of the Act basically being ignored in terms of the day-to-day care of the mentally incapacitated. That is obviously something to be regretted. My last point relates to the Court of Protection. In my opinion, it is not an appropriate forum for bread-and-butter welfare cases, if I may use that term. Serious consideration should be given to an alternative tribunal structure.

Moving on to DOLS, I have five brief points to make. Perhaps I may quote from myself when I wrote about DOLS in 2008, when I said that, “DOLS is a procedure that has been created that is hugely complex, voluminous, overly bureaucratic, difficult to understand and yet provides mentally incapacitated people with minimum safeguards”. Since then I have had no cause to resile from that statement.

Secondly, the Department of Health, in a circular published in 2010, reported that DOLS had been “successfully implemented”. I think that that was a wildly optimistic judgment to make in 2010. There is a lot of evidence to suggest that the opposite is the case. Most of this evidence will be familiar to the Committee. There are huge regional variations in the application of DOLS. Fewer than 1% of patients who are subject to DOLS make an application to the Court of Protection for their release. Some cases indicate that DOLS has been used as an instrument of oppression, where local authorities acting as supervisory bodies have used DOLS to get their way, in a sense. I am thinking in particular of the Neary case, and also of a lady called Peggy Ross, who comes from Cardiff.

Thirdly, the relationship between the DOLS legislation and the Mental Health Act is not clear. People do not understand it. That is totally understandable, given that there are two parallel pieces of legislation, both allowing for the detention of mentally incapacitated people. There is bound to be confusion, and although, again in evidence last week, you were told that the relationship is now well understood, you were given an example by an official which suggested that she did not understand the relationship between the two Acts. It was an example relating to Winterbourne View.

Next, I think that the protections given to patients who are subject to DOLS are far, far less than the equivalent protections given to patients who are detained under the Mental Health Act. There is a long list. I will not go through it, but it relates to patients who are sectioned having free after-care and automatic access to a tribunal if they do not apply. There are also major provisions in the Mental Health Act that protect the Article 8 rights of patients, in particular the consent to treatment provisions. There is no equivalent in DOLS. In fact, in a very recent case a judge complained that the DOLS legislation was silent when it came to the Article 8 rights of patients.

It will be clear from what I have said so far that I am not desperately in favour of the DOLS regime. Parliament did not undertake its proper duty when DOLS went through both Houses—with the notable exception of Lady Browning who, when she was an MP, was one of the few parliamentarians who spoke on the DOLS proposals. When the two schedules—AI and IA—that make up the DOLS procedure went through Parliament, there was not one word of parliamentary debate*. Not one word. Those schedules comprise more or less 200 paragraphs. In statutory terms, a paragraph is the equivalent of a section of an Act. So a

Ms Nicola Mackintosh, Ms Katie Johnston, Professor Richard Jones and Ms Kirsty Keywood
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major Act of Parliament dealing with the liberty of the citizen went through Parliament without one word of parliamentary debate. With all due respect, I think that is scandalous, and Parliament has a lot to answer for. But we are where we are. What shall we do? In my opinion, the DOLS regime is so complex and interlinked that it is impossible to amend.

* Since giving my evidence, I have discovered that there was a debate on two paragraphs of what is now Schedule A1 at the Public Bill Committee hearing on May 15, 2007. I should therefore have said that there was virtually no debate on the two Schedules.

The Chairman: I think we will probably come on to these issues, Professor.

Professor Richard Jones: I am sorry if I went on too long.

Q26 The Chairman: I want to ask the first question, which to some extent has been answered by some of your comments. However, I would like to hear any additional views you have, as well as those of the other witnesses. When the Act was passed, it was widely viewed as being a progressive and welcome piece of legislation. Has it lived up to those expectations? Have there been any unanticipated consequences? What changes, if any, would you make to the legislation?

Katie Johnston: I think Liberty would echo everything the professor said, including the fact that the Mental Capacity Act, when it was passed, was rightly seen as a progressive piece of legislation. It moved away from paternalism towards the enhancement of autonomy, which is welcome. From our evidence and what we have seen, the problem with the Mental Capacity Act is really one of implementation, and a lack of understanding among those who have to apply it on the ground.

Liberty is currently advising a lady whose father was taken into hospital when he was in his 90s after a stroke. He was given an intranasal tube to feed him, despite his expressed wishes to the contrary in the past. When his medical records were examined, it was clear that he had not undergone a proper capacity assessment for two months. Even though he was assumed to lack capacity, there was recorded evidence of him giving consent—although if he lacked capacity, he was obviously incapable of giving that consent. He was discharged. So we think that the Act is good. We obviously have problems with DOLS, which we will address later, but the problem with the Act is one of implementation.

Kirsty Keywood: Perhaps I could add to that. One of the unanticipated consequences from my perspective, interested as I am in adult protection issues, is that it is absolutely true to say that the Mental Capacity Act had a very empowering ethos behind it. However, what we have discovered since the enactment of the legislation are the very serious harms that many vulnerable people have come to. In reviewing their experiences, many of which were profiled in serious case reviews, and perhaps most prominently in the Winterbourne View case, it is quite clear that we have had a series of developments in policy and also in law that should force us to think carefully about how we balance empowerment and provide vulnerable people who have challenges around decision-making because of their circumstances with protection. I will offer you a few examples of that.

One of the difficulties that I have seen in practice—I suppose this echoes Richard’s point about training and understanding at the coal face—is that I am aware of a number of people who have either failed to receive care or have “chosen” to disengage from beneficial services when relevant agencies have not asked questions about whether the decision to refuse care was a capacitous one. When pushed by people like myself to explain why, with a person

whose decision-making at least raises concerns or questions that need to be answered, an assessment of capacity did not take place, the answer came back, “Well, there is a statutory presumption of capacity. We did not know that we had a basis to ask questions and at least interrogate the basis of the decision”. Clearly, that is not legally correct, but there is something about the presumption of capacity as it is currently worded in the Mental Capacity Act that has obscured the thinking of a number of people working at the grass roots.

I will offer one example. I was involved in a serious case review of a man called Steven Hoskin, who was tortured and murdered by a gang, many of whom were convicted following prosecution. He was entitled to a community care service and was receiving support to manage his finances. Steven lived in a bedsit that accommodated one person but at the time when he disengaged from services, a number of people were living with him. He was not capable of expressing free choices at all, yet his decision to decline the service was not interrogated. It would be quite beneficial, if any reforms to the Mental Capacity Act are to be made, to clarify that it is simply not reasonable, where a person is exercising a choice that results in significant harm, not to undertake an assessment of capacity. That is not to say that their decision should be overridden, but we should ask searching questions about whether the decision is legally valid. That is one issue that has arisen with regard to adult protection.

The other issue is that the courts have now taken it upon themselves—quite rightly, in my view, given that we have no legislation—to provide some kind of legal remedy and course of action to protect vulnerable people whose decisions are the product of considerable constraint and abuse by family members in some cases, or by friends. What the Mental Capacity Act, at least in the code of practice, needs to do is make it very clear to people working on the ground exactly how adult protection law and the Act work together. I have seen enough horror stories involving self-neglect and abuse to indicate that those lines of connection need to be made much clearer, not just to people working on the ground but to the lawyers who are advising them.

Q27 The Chairman: Ms Mackintosh?

Nicola Mackintosh: I will echo some of what has been said. Richard and I probably disagree on a few issues, which we will come to later. I think that the Act is a good start. My practice is in community care, and was in mental health and homelessness pre-MCA. Before the Act came in, obviously there was no legal structure for decision-making and the assessment of potentially mentally incapacitated people. My concern is at the way it has been implemented. Often in my practice, I see decisions being made by statutory agencies on behalf of vulnerable people who may or may not lack capacity, under the guise of best interests. I echo what was said about the answer being, “Does the person have capacity?”, and the outcome being led by resources. I see lots of cases where a person has been neglecting themselves, and the local authority or the relevant health agency has used the presumption of capacity to allow that to continue. Equally, I have many, many cases where my clients have been deemed to lack capacity because the outcome is going to be that the state spends less on them. That is one of my concerns.

Most people who are affected by the Act have no independent advocacy. They do not have access to an IMCA or to relatives. A lot of people with particularly severe disabilities—challenging behaviour and so forth—are less likely to have family and friends involved in their welfare. One of the things that could be done is to bolster the advocacy services and the right to independent advocacy over a larger range of decision-making than is the case under the current IMCA scheme.

Winterbourne View, in my view, is just the tip of the iceberg. Every single case I deal with—and I deal with these cases day in and day out—is an example of the abuse of a vulnerable person. I have not had one case where there has not been financial, physical or psychological abuse, and in many cases there has been all three. Safeguarding is a big issue. You ask, “What could we do? Could the legislation be changed?”. Yes. There needs to be a safeguarding Act. There needs to be protection against cruelty and the abuse of vulnerable people.

Professor Richard Jones: Can I come in briefly? One of the themes that has come out from my colleagues is something that I very much agree with. Most decisions made on behalf of mentally incapacitated people are not preceded by a capacity assessment or a best-interests evaluation. Carers just get on with it. One of the needs that there is in terms of the legislation and perhaps the code of practice is to identify when a formal capacity assessment and a formal best-interests judgment need to be made. The code of practice at the moment refers to complex decisions needing a formal capacity assessment. That is not sufficient. Many simple, straightforward decisions relating to a mentally incapacitated person can be extremely important for them. They can be crucial. “Who do I live with?”. That is not necessarily a complex issue, but clearly it should be preceded by a formal capacity assessment and a formal best-interests judgment. That is where the Act is in danger of coming into disrepute. The vast majority of decisions are not made in compliance with the Act. As I said, people just get on with it. So when is it that there should be a trigger for the formalities of the Act to be complied with?

Q28 Baroness McIntosh of Hudnall: Professor Jones, could I ask you something in relation to what you just said, and indeed to what everybody else said? I was wondering about the differences in practice between formal and informal care. I am no expert, and nor am I somebody who has great experience in this area, but it strikes me immediately that the implementation issue is very much harder to follow through where people are in the care of their families, for example. Indeed, it may be—this is a question—that there should be different ways of looking at how those things are followed through in informal settings. Have you any observations to make about whether this is an issue?

Professor Richard Jones: First, we do not know what goes on behind the vast majority of doors where mentally incapacitated people are being cared for. My own view, which is not really based on hard evidence, is that there will be little difference between what a family carer and a care assistant in a care home do in relation to formal assessments and formal best-interests judgments. A care assistant looking after a resident of a care home is not going to go through that process when a decision is made—for example, when should that person watch television? When should that person go out into the garden? What should that person wear?—all the trivial decisions that have to be made. It just does not happen.

Baroness McIntosh of Hudnall: I am sorry to interrupt you, but within formal care settings there is presumably some sort of hierarchy within which, in theory, somebody who has a daily responsibility for those sorts of decisions ought to be able to refer up any issues that they might have or indeed be instructed, which would not be the case in an informal setting. This may not bear further examination; I am just interested.

Professor Richard Jones: That may happen, it may not happen; we do not know. There is nothing in the code of practice or the Act to focus on that issue.

Kirsty Keywood: I have certainly spoken to many family members and carers who have felt desperately unsupported in the very onerous task of facilitating someone’s decision-making when they lack capacity. Something that has struck me over the years—and it comes back to something that Professor Jones said earlier—is that the Court of Protection, as a vessel of

advice and legal guidance, is so removed from the experiences of most family carers that there is nowhere for many of them to turn to in order to get some support and advice.

I am particularly concerned about individuals who are self-funding in care homes. We know that they are not subject to the same kind of scrutiny and practice. Families have very limited opportunities to access support unless they are prepared to take the tortuous and financially difficult road of approaching the Court of Protection. Access to justice for informal care-givers is a real problem. Partly for that reason, I support the view that a tribunal system that operates much closer and is much more accessible to family members and informal care-givers might be able to resolve some of these quite complicated issues. We see this happening in other countries. It is not beyond our capability to do it here, but it comes with a price tag, of course.

Q29 The Chairman: You mentioned people who are self-funding in care homes not having anyone to assist them. My mother was in a care home for three years. She was self-funding but she also had a local authority social worker who worked out her care plan for her. This was in Scotland—I do not know if that is unusual.

Kirsty Keywood: She is lucky. I have been given permission to tell you this story. Dr Margaret Flynn told me of a case concerning a lady who was a self-funder who was placed in a home that the local authority had refused to engage with because of the poor standards of care; yet this home was continuing to take self-funders. This lady's only living relative was not able to advocate and inspect the circumstances at that home. The lady died, and nobody was able to offer any kind of intervention or scrutiny. We can say that there are bad care homes and there are good care homes, but there are a awful lot of care homes where people are self-funding and do not have ready access to any kind of advocacy service and family members may simply not be close enough to offer that kind of insight and scrutiny of what is happening.

Baroness Browning: Perhaps I might add that one of the critical points for self-funders is when their needs change, very often from when they change from needing care to needing professional nursing care. The classic fractured neck of femur is the critical point in decision-making at which some homes can no longer cope with somebody who is not weight-bearing. But it sounds from what you have just said that if there are no family members around to help through that process of change, that is when those areas of weakness show a lack of proper care. Is that right?

Katie Johnston: I will say that the problem of self-funders is exacerbated by what has become known as the YL loophole, which is that, as the law currently stands, persons who are in a self-funded care home or residential home are not subject to the same protections of the Human Rights Act as they would be if they were in a local authority-funded care home and they were placed by the local authority.

On an unrelated note, there is often delay in appointing an IMCA—the independent mental capacity advocate—and one of the reforms that we would consider would be that if the representative appointed for the person lacking capacity were a family member or a friend, instead of leaving the care home with more flexibility in appointing in the IMCA, that should be automatic to ensure a ready means to access justice.

Nicola Mackintosh: Just to add to that, my practice goes back more than 20 years in community care law and I have seen practice changing. We no longer have the old-fashioned social work, the therapeutic work between social workers and families or individuals, which we used to. We have a very different system of a single one-off assessment of needs

followed by a brokering of a care package, and then effectively the case is closed until the next review, which might be a year hence. For those cases, whether they be self-funders or other people who are funded by the local authority, perhaps in a care home, the case is effectively closed to the statutory services for quite a long period of time. In my experience, where a social worker is allocated to the case and has ongoing involvement with that person, that involves a much greater degree of protection—not always and not always brilliantly—for that person. So it is about old-fashioned social work going out of the window and being replaced by a simple one-off assessment and then brokerage, which is a real problem.

Q30 Baroness Browning: Perhaps I might come back to the question that I was going to ask you: when this Committee concludes, our report will show, I hope, from the evidence we have received, what needs to happen to make the Mental Capacity Act more effective and fit for purpose. I am basically saying that I not think it is fit for purpose. In fact, we were told last week by officials that, “Overall, our view is that the Act has been a success”. I would say that, like the curate’s egg, parts of it may have been a success but other parts of it are seriously lacking. You have all started to outline to us where tangibly you see change and where change might make it better.

We have received from Liberty the letter that Shami Chakrabarti sent to Dr Hywel Francis at the end of last year asking his Committee to look at reviewing this Act. At the same time, I wrote to Dr Francis to ask if his Committee could do it, having had a conversation with Dr Margaret Flynn, who did the report on Winterbourne View, in which I discovered that the Act had not been used—had not even been mentioned—at Winterbourne View. You have all clearly had a lot of experience in coming to the conclusions that you have shared with us this morning. Clearly, by November of last year, Liberty had come to the conclusion that something needed to happen. Before that letter was sent to Dr Francis, had Liberty—had any of you—made representations to the two departments that we took evidence from last week?

Katie Johnston: I do not believe that we have, but I can check and respond in writing.

Baroness Browning: I just wondered if the letter to Dr Francis was as a result of having had discussions with government departments. I was interested to know what their response was to any representations you may have made.

The Chairman: It might be useful if you could check that and give us a handwritten note.

Katie Johnston: I will.

Baroness Browning: If the panel is able to share any of that information with us, it would be very helpful because if we do recommend any changes, is the Government whom we have to persuade of our views.

Professor Richard Jones: Whatever changes may or may not be recommended and perhaps translated into a new code of practice or an amendment to the Act, the current situation will still obtain, in that many people will not be aware of the new, better legislation. Perhaps the Government should use, if not their power then their influence to ensure that all relevant professional bodies—not just health and social care professionals but housing managers, bank managers and the police—have the Mental Capacity Act as part of their basic core curriculum. It should be bedded into basic training. It is not at the moment. That could have a significant impact in the longer term, perhaps. Apart from that, I do not think that a

new, very expensive training initiative will be particularly helpful. I wonder whether some consideration should be given to funding a public information campaign about the Act.

Q31 Lord Swinfen: I think that you have probably just answered my question. I was going to ask whether we have enough people with the right qualifications and knowledge to help people who are mentally incapacitated. Do we have a great shortage of such people?

Professor Richard Jones: There are a lot of people there who are providing help, but a lot of them are not aware of the Act and of their responsibilities under it. That is my experience. I am referring to people you would expect to know the Act—surgeons, for example. I was involved in a case not long ago where the surgeon who was refusing to operate on somebody because he was not able to give consent did not know about the Mental Capacity Act. He was totally ignorant of it. That is an awful state of affairs.

Lord Swinfen: Do people who are actually working with people with a mental incapacity have the appropriate knowledge of that incapacity, let alone of the law?

Professor Richard Jones: I do not know, frankly. One of the problems is that the Act makes certain assumptions about the ability of individuals to assess capacity. I know a fair amount about the law. I was trained as a social worker many years ago. I do not feel competent to assess capacity, apart from very straightforward cases. It is a very skilled activity, but we assume that people have this skill. I question that.

Nicola Mackintosh: I support the need for training. Training on the Mental Capacity Act and its principles should be embedded in—I agree—housing officers, but also in all nurses, doctors, social workers, teachers and everyone in society. If the citizenship programme still exists, it should be part of that. Young people growing up in schools should be able to tell their parents, so the message can be imparted more widely. I would like to see—this may sound rather dull—standard forms for assessing capacity. They need not be very complicated, but, in my experience, having a standard form encourages a) a great paper trail of decision-making, and b) the correct procedures being gone through in terms of different levels of decision-making.

I echo what was said also about the lack of awareness, particularly within the NHS. I have had cases of vulnerable people who, were it not for the intervention of the Court of Protection, alerted by relatives, would have undergone very invasive, permanent, irreversible surgery because of the tendency to use the Mental Capacity Act in a best-interests, paternalistic way, particularly within the medical profession and the NHS. That is a real issue. There is a different ethos in terms of the social model of care, particularly with regard to people with learning disabilities. It is different for different client groups. For people with mental health needs and people with dementia, a different approach is taken from that taken with people who have learning disabilities.

Q32 Baroness Shephard of Northwold: It would be interesting to hear the views of the panel on the different requirements of this Act, and the clients with whom it deals, and the provisions of the Mental Health Act. I come new to this, but I have some knowledge of the Mental Health Act. It seems that it is infinitely more complex because you are involving families, carers and a lot of informal settings. You have already said that there should be training for X, Y, Z and the rest of it, but what about families and carers? You are then going into the realms of unreality. It may be desirable, but there is no way that you can get into all of that. You pointed out a lacuna in the area where people are self-funding in residential settings. Again, we are dealing with families—perhaps distant families. I do not see how you

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could achieve all of this. You could certainly put a lot of it into training the most obvious groups of people who might have to deal with the situation, but you are still leaving a huge area of vulnerability where people are being informally cared for, or looked after by care assistants and so on. How would you tackle that? That would be what Ministers would ask. They would say, “Okay, here is a gap. How do we fill it?”

Kirsty Keywood: I do not have the answer, but I do have some thoughts. On the interface between the Mental Capacity Act and the Mental Health Act, as a lawyer I am very drawn to the safeguards that are present in the Mental Health Act. However, what was really interesting about the engagement exercise that the Department of Health did with people with learning difficulties, and also family members and informal carers, was that they preferred the Mental Capacity Act to the Mental Health Act. It could be, of course, that the Mental Health Act was the vehicle for the majority of the appalling treatment that happened at Winterbourne View. But there is something there that we have to acknowledge. There is something about the Mental Capacity Act that family members seem quite drawn to, when faced with a choice between the two pieces of legislation.

Baroness Shephard of Northwold: I think that in people’s minds, the Mental Health Act may be the equivalent of detention.

Kirsty Keywood: Yes, and quite stigmatising.

Baroness Shephard of Northwold: Yes, in the mind but not necessarily in reality.

Kirsty Keywood: Indeed. One of the things you talked about really struck a chord with me. We are going back to the issue of training. Very often we are dealing with people who are extremely poorly paid for the very important work that they do.

Baroness Shephard of Northwold: Exactly so. This is why I mentioned care assistants.

Kirsty Keywood: Quite. We need a more effective scheme to regulate the professions, including care assistants. I know that work has been done to introduce and develop NVQs in caring. Certainly mental capacity training has to be part of that. In that context, I would add one rider to the discussion we have had about training. Most of the training that I have been aware of that has happened around mental capacity has been about giving people knowledge. Lots of people will know a bit more about mental capacity after they have had a training session than they would if it had not taken place. But what a lot of training does not do is equip people with the skills that might be useful to undertake a determination of capacity and, from that, formulate an assessment of best interests. So it is not just about training but about skills-based training that will be appropriate to the particular professional groups that are working in those areas.

Lord Swinfen: Ms Mackintosh suggested that she had designed a form that might be useful. Perhaps we could see it.

Nicola Mackintosh: No. I suggested that it would be possible to devise such a form. It would have to be very simple. One problem that we will probably get on to in relation to DOLS is complexity. A key issue is keeping things simple but making sure that they work.

Q33 Baroness Barker: I declare an interest; I should have declared it last week. I own a consultancy which works with charities. From the discussion this morning, and also from last week, I think it would be fair to make the assumption that the principle-based approach to the Mental Capacity Act is one which, with the possible exception of the statutory presumption of capacity, has worked fairly well, and that is what people see as being part of

the success of the Act. On the other hand, the area of practice has not been as successful. Those of us who were involved in the legislation all those years ago believed that going down the route that we did, of principle-based legislation, we were constructing something which would endure.

My question to you is: do you think that is right, and that the principle-based approach has given us a piece of legislation which is sufficiently flexible to deal with a changing world? There are two changes I would point to: one is the increase in dementia. You will know about the Prime Minister's challenge—the idea that there should be dementia-friendly communities. Well, dementia-friendly communities have to have people who, in the course of their everyday work, are capable of dealing with that dementia. The other is the rise of technology. We did not think of technology when we did this legislation years ago, but technology is so much part of people's lives now. I think that throws up some very interesting questions, and I would like to hear your views on that.

Professor Richard Jones: I think you are being slightly sanguine in terms of the principles being applied, apart from the exception you note. We do not really know, because we do not really know that well how the Act is operating, but there is some evidence to suggest that the least restrictive alternative principle is not being complied with. I am thinking particularly of the research that I think the Alzheimer's Society published recently, which showed that 60% or thereabouts of patients with dementia who were admitted to hospital were admitted from their home, but only 30% were discharged back to their home. That raises the question of whether sufficient attention was given to a robust care package being put in place to support somebody at their home. Obviously, cost comes into this. Because of the general low level of knowledge about the Act, we cannot really say that the principles are being applied as you—as legislators—hoped.

Kirsty Keywood: I think that is right, is it not? People I speak to on the ground report really positively about the principles—there is no doubt about it. They say that they find it very useful. So on one hand I have this very positive feeling, and on the other hand I look at the research that is being done on decision-making—and that does not form a solid national picture either, but we know, for example, from the research literature, that people tend to conflate issues of capacity with best interests, as we have seen already. That is a huge problem, that in some circumstances the desire to be protective can mean that the most restrictive alternative is not always adhered to. There will always be challenges in implementation. I am not really sure how to answer your question, except that I know that the people I have engaged with on a professional level report very positively. Symbolically, it was a very important thing that the legislation did, and I, for one, am very glad that they are there.

Professor Richard Jones: They are a bit motherhood and apple pie, are they not?

Kirsty Keywood: Yes, they are, and the devil is in the implementation, as we have seen.

Katie Johnston: As I said, we think the principled approach is very good. When you have legislation that involves principles a problem comes in how they are applied on the ground when there is a lack of specificity in the primary legislation. If the Committee wanted to recommend one simple and relatively easy thing to do it would be to update the code of practice. Quite often the legislation is great but it is just not implemented correctly, or the code of practice is wonderful but is just not followed. This is particularly important given the breadth of the powers that are granted in Sections 5 and 6 for carers to take best-interests decisions. Really, quite urgently a review of the code of practice would be really helpful.

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Nicola Mackintosh: I completely agree with that. The principles are great; there is a slight concern about Sections 5 and 6 being geared towards protection of the carers rather than the rights of the vulnerable person being absolutely at the centre of all these decisions. I completely agree that the code of practice needs updating. I would say that the code of practice in many areas, in its case examples, is motherhood and apple pie. A dispute arises but over time, having talked together, everybody sorts everything out and everybody is happy. My experience—obviously, I only see those cases which present more significant problems—is that perhaps that is not always the case.

Often, talking is a great way of sorting things out, but sometimes it does not work.

Baroness McIntosh of Hudnall: We did raise the question of the code of practice and the potential it has for being reviewed last week with the department, as at least Professor Jones will know. The answer they gave seems to me one that perhaps you might want to reflect on for us. That is, the issue is not that the code of practice needs to be reviewed—that may or may not be true—but that it is to do, as you have said yourselves, with how it is implemented on the ground. I wonder whether a lot of work going into a revised code of practice, without there being some further pressure put on the people whose job it is to implement that code to do so, is really going to make any significant difference.

Katie Johnston: I think you are right. There is a problem of implementation, but there is also a problem with the code. One example is the definition of deprivation of liberty—this is about DOLS. There have been at least 16 or 20 cases that redefine deprivation of liberty which are not reflected in the current definition that is given.

The Chairman: That is the subject of litigation at the moment.

Katie Johnston: Yes. In the autumn.

The Chairman: I think the Supreme Court will be adjudicating upon that in October, so we may get some guidance on that.

Katie Johnston: I hope to be able to comment on that today.

Q34 Lord Patel of Bradford: I am going to take you back to the deprivation of liberty safeguards. It seems we have two opposing views at the moment. Last week I asked the question to the departments whether, as some practitioners have said, the DOLS was a bit of an add-on to the Mental Capacity Act. It is there with a very different ethos. Their response seemed fairly unequivocally, “No, that is not the case, because there is too much focus on the deprivation bit and not enough on the safeguards element”. You are obviously saying some different things. I will play devil’s advocate a little bit and say, if we did not have DOLS, what we would have is probably thousands of people who are de facto detained. The other option is to section them all, get second opinions, provide Section 117 aftercare—the resources are just not there. Is this the best of a bad job?

Professor Richard Jones: I would say the better alternative, which in fact was flagged up by the Department of Health when the consultation exercise on DOLS went through, would be to amend the Mental Health Act—amend the guardianship provisions in the Mental Health Act, which to all intents and purposes at the moment allow for detention—to incorporate the DOLS population, so they would not be subject to the same mechanisms as a detained person would be subject to, but they would have the protections of the tribunal system and they would have the protections relating to monitoring of correspondence if the Act was amended properly. So you could tailor the guardianship provisions to meet the DOLS population but without full-blown sectioning being required.

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Yes, there would be expense, but in my opinion it would not be as expensive as the current DOLS system, which is extremely expensive, because a whole new structure has been set up.

Katie Johnston: The situation that you outline where thousands, if not tens of thousands, are being de facto detained unlawfully is what is going on at the moment. Liberty's main problem with the Act from a human rights point of view is that there are thousands, perhaps tens of thousands, of people who are deprived of their liberty in the sense of Article 5 of the European convention, and who are not subject to the safeguards guaranteed in Article 5.4 of the convention or even in DOLS because for a number of reasons, which I can go into, there is a great lack of awareness among people who should be assessing whether a DOLS order is required, when it is required and if it should be applied for. It has proactively to be applied for by the people in care homes. So, for various reasons, people are being detained at the moment, which is the one of the biggest problems.

Kirsty Keywood: I think there is a real irony with DOLS, which is that it was brought in precisely because our common-law regulation of this issue was in breach of European human rights law because it failed to offer clarity to individuals who need to know in advance what their rights are. Quite what clarity the DOLS provisions offer to anybody is a mystery to me. We may well have a legal solution to a problem which is still in breach of human rights law.

I absolutely agree with Professor Jones. Guardianship would have to be revised to accommodate some of the issues that relate to deprivation of liberty, but that is doable. Interestingly, my colleague Neil Allen at the University of Manchester is working in the Isle of Man to review its response to DOLS. The Isle of Man is working up a suggestion that guardianship is used as the mechanism to authorise deprivation over there.

Q35 The Chairman: Do you know how far that has got?

Kirsty Keywood: It is hoped to have legislation by 2015, I understand.

Nicola Mackintosh: We all know that there are major problems with DOLS, but I have experience of cases that have come to court because the RPR, on behalf of the incapacitated person, has made the application or has assisted the person to make the application to court. I have seen examples of where it has worked in at least two cases, both of people placed in care homes after having been discharged from hospital who had consistently expressed a wish to go home to their own homes. In one case, the judge of the Court of Protection felt that the strength of feeling of that person was so important in his decision-making that he visited her in the care home, which is an example of very good flexible practice, which is what you need from the judiciary in this area. So there are examples of where it works very well, but I completely agree that the vast majority of my clients in care homes are being deprived of their liberty without any protection at all.

Whether guardianship is the right way forward—and I have some concerns about a single person being appointed as a guardian, which dates back to the Mental Health Act 1959 and the paternalistic approach which was taken then, which is precisely why the powers in guardianship were narrowed in the 1983 Act—I do not know. I certainly think that the current safeguards have an important element to them. The crucial element is that there is an independent person who is funded and whose responsibility is to review with the vulnerable or incapacitated person and if necessary to assist them in bringing the case before the court. However, even so, only a very small percentage of those cases are raised before the Court of Protection.

Obviously, there is some need for some research on the reason why that is the case. I suspect it will be because if you have a vulnerable person detained in a care home who is physically or verbally expressing a wish to leave, those cases are more likely to be raised before the court than cases involving a compliant, incapacitated person. That was the case in the Bournemouth case. I do not think the DOLS scheme has cured the illegality.

Lord Patel of Bradford: Can I just take this a little bit further? If this was an ideal world and the training and implementation were there and we saw more of the cases that you are dealing with where it has been a success, is there actually a problem with the legislation? Would you bother to change the legislation then or is it still flawed?

Professor Richard Jones: I defy anyone to read Schedule 1A to the Mental Capacity Act and say, “I understand this. Gosh, it’s straightforward”. It is devilishly difficult to understand. Judges have complained about the impenetrable nature of the legislation, so even if the structure was right, the wording would need to be substantially changed so that it is not just people like us who understand it. The citizen should understand this legislation that is concerned with depriving them of their liberty. It should not be so impenetrable.

Q36 Lord Swinfen: The Mental Capacity Act applies to Wales with different implementation arrangements. Northern Ireland and Scotland have different legislation entirely. Are there any lessons that can be learnt from that different legislation or, indeed, from international law or other nations’ laws? If so, what?

Professor Richard Jones: Speaking as a Welshman, I do not think there is anything, I am afraid, that you can learn from Wales. It has been implemented in Wales in exactly the same way as it has been in England, fortunately, because if you look at the Mental Health Act, there are different regulations, different forms and a different code of practice which leads to its own complications, so the fact that it applies in Wales as it does in England means there is nothing you can learn from Wales.

Lord Swinfen: What I meant was: is there anything that you can learn from Scotland or Northern Ireland or from, say, France, Germany or the United States? I know that, in the eyes of the Welsh, Wales always lead the English, and I would not argue with you on that—you are bigger than me—but what can we learn from the other nations of the world?

Professor Richard Jones: I think Kirsty is the expert on this.

Kirsty Keywood: I think there is an awful lot we can learn from what is happening in other jurisdictions. Your special adviser can tell you more than I can about the UN Convention on the Rights of Persons with Disabilities, but that signals some important changes that are ahead. Northern Ireland, as you know, is going through a very lengthy process of law reform in the field of mental capacity and is proposing to have a fused piece of legislation that incorporates mental health and mental capacity law, so the concept of capacity will have far greater significance in mental health decision-making than it has at present in Northern Ireland or in English mental health law. That is a very interesting approach to think about.

More specifically, the Mental Capacity (Health, Welfare and Finance) Bill, as it is currently framed, is anticipating a more robust set of safeguards for certain sorts of decisions, and I find that quite appealing in view of some of the concerns that I have mentioned here. For example, under the current Bill, where a person is objecting to an intervention that is not routine or urgent, a nominated person has to be involved—an advocate of some sort—and there has to be a referral to a multidisciplinary panel.

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Northern Ireland is taking an interesting approach, which is almost to tier decision-making. You have the informal decision-making that will happen at home, the very routine sorts of interventions, such as bathing, cleaning and dressing, and then you have a gradation through to the more serious ones where there will be far more intervention by third parties and multidisciplinary panels. That approach appeals to me because of the safeguarding concerns that I have seen.

Scotland is quite interesting because it has produced a statutory footing to its adult protection law. It has not put adult protection and mental capacity in the same piece of legislation, but the two cross-refer to each other extensively. In consequence of that, the code of practice on mental capacity in Scotland and the guidance that has been issued by a number of the professional organisations are very alert to the need to balance capacity with adult protection. That is a really useful lesson that I am aware of.

The UN Convention on the Rights of Persons with Disabilities has a lot to tell us. I am not sure that we all entirely understand quite where it is going to take us, but certainly it talks about the importance of developing systems of supported decision-making rather than proxy decision-making. This idea that if a person lacks capacity, other people move in and make a decision on their best interests is not really within the ethos of the UN Convention, and some countries have been taken to task for having legislation that does just that. So when we think about redrafting the principles, one of the things that, if we are to take the Convention seriously, we should recognise is the importance of taking steps to support decision-making and to acknowledge the will, preferences and rights of individuals. That does not mean that they will always be respected, but they have to be the starting point for any kind of determination of what is best for an individual. That is a really important lesson that we have to take forward because legally we are required to do so.

There are other mechanisms that the UN Convention may require. It may be that we have to provide greater scrutiny by third parties of decision-making. We may have to reformulate the best-interests checklist as it currently features within the legislation to acknowledge the primacy of the person's wishes and interests. We will get a clearer picture of what the UN Convention expects of countries such as ours when it issues its report on the safeguarding of disabled people in Australia later this year. I think there will be some lessons we can take from that, and that is due in September.

Q37 The Chairman: Baroness Shephard?

Baroness Shephard of Northwold: Well, Lord Chairman, my question is No. 5 and I feel that it has been most comprehensively discussed and answered, in so far as there is an answer. The answer is that the implementation could be very much better across a wide range of issues. The most concrete suggestion that we have had is that it might be a good start to look again at the code of practice. I do not think that there is any more I can ask.

Baroness McIntosh of Hudnall: One thing we could explore a bit further is something which you raised, Ms Mackintosh, which is the question of the IMCA system and whether, in your view, it is either properly understood or accessed by the people who need to access it, and whether it is really helping to provide the voice that it should for people lacking capacity. If I recall your earlier answer correctly, you have some doubts about that. Perhaps you would like to start off.

Nicola Mackintosh: A bit like the Act, it is a good start. I have experience of very good quality service being provided by some IMCAs and not by others, but you will have that in

any system. The difficulty is that the IMCA input is severely limited at the moment. It could positively be expanded.

Baroness McIntosh of Hudnall: Could I stop you for a moment? When you say it is limited, what is limiting it?

Nicola Mackintosh: I am not privy to the details of the commissioning arrangements between, for example, local authorities and advocacy organisations, who tend to provide the IMCA service. Anecdotally, what they have told me is that the actual time an IMCA is permitted to spend on a case which has been referred to them is limited in terms of either money or hours' worth of work, or it is limited to a specific decision rather than being part of ongoing generic advocacy, particularly for people who have a range of difficulties and issues which might be coming up. That might be, for example, residence; it might be difficult relationships with family members and contact arrangements between the vulnerable person and their family members, within a care home, for example. There may be a plethora of quite complicated issues for a single person. The current IMCA service is very limited to just a single issue; for example, a change of residence. That might be two, three or four hours' worth of input from the IMCA, which is not really long enough to spend time getting to know the person, listening to their wishes and feelings and really ascertaining what is going on for them as a human being. That is what it comes down to at the end of the day. The IMCA could provide a pivotal role in ensuring that independence of voice for the incapacitated person, but without so many of the artificial limits which are currently being placed on them.

Baroness McIntosh of Hudnall: Which, if I have understood you, you suspect may be to do with—referring to something else you said, and forgive me for a moment, but I want to get this right; I think I wrote it down somewhere—services being “outcomes led by resources”. So your suspicion is that the limitations you have just described are brought about by an unwillingness or inability by commissioners to commit those resources.

Nicola Mackintosh: It can be. There is also a structural change that has to take place. Currently there is a self-restriction that referral is only made for an IMCA with regard to certain decision-making. That could be expanded. There is discretion to use the IMCA service—make a referral for an IMCA—in relation to the vast majority of decisions. But in practice my experience is that it is only in relation to a change of accommodation. Even then it is not followed all the time. There are very clear cases where, for example, someone is being discharged from hospital. There should be an IMCA in every single case where the person is assessed as lacking capacity.

Q38 Lord Patel of Bradford: Following on from that, obviously then the difference is with the advocates that are provided for detained patients under the Mental Health Act. Is there a quality aspect, that they are different and they need better access to them?

Professor Richard Jones: I do not know the answer to that question, I am afraid. It is a fairly new initiative, the independent mental health advocates, and their role is perhaps more focused on explaining the statutory scheme as opposed to that of the IMCA who identifies what course of action is in the best interest of the individual concerned. The IMCA scheme has a lot to commend it. From a negative point of view, I have not had much experience of the scheme, but the involvement of the IMCA can lead to delays in terms of the decision being reached. My own experience, which is focused on decision-making in hospitals, is that the IMCA very rarely disagrees with the best-interests decision that is being advocated. So I am not sure what actual impact the IMCA has in terms of changing minds.

Kirsty Keywood: I think that the issues around IMCA involvement with serious medical treatment have had that impact. We know from the research that IMCAs have said that they very much find when they are advocating for somebody who is facing a serious medical intervention that the clinicians sometimes do not feel that they [the IMCAs] have expertise to be there, offering that role. When it comes to accommodation decisions the picture is slightly different. Very much like Nicola, I have a strong sense that IMCAs can work incredibly positively to advocate for people who lack capacity. They are very much restricted to circumstances, by and large, where the person without capacity has no family member or unpaid carer. There are exceptions to that; for example, in adult protection you can have an IMCA if your local authority decides that it is appropriate, even if you have family members around. Generally, however, there has to be nobody in your informal caring network who can act as an advocate for you before you get an IMCA. As we have seen today, there are certainly circumstances where relatives may be distant and where there may be such conflict among relatives that actually an IMCA could be quite an empowering tool for some sorts of particularly complicated decision-making. I would certainly welcome the opportunity to confer the power on health commissioners and local authorities to deploy IMCAs in a wider range of circumstances.

Q39 Baroness Browning: Two of you have now mentioned family members. Of course, I understand that there are often disputes within families and an IMCA will be very important in those circumstances. Could I take your view on where we are as far as the Act is concerned with carers and close family members being advocates? I should declare an interest, which is in the list. I am sorry that Baroness Hollins is not here today, because she would also share this feeling. We have had some pretty shocking cases, particularly the Mencap cases that have been documented, where mothers have stood by the beds of adult learning-disabled children who have died, not because of the illness they have been admitted to a general hospital ward for, but because of neglect, because the staff have had a difference of opinion with the parent—the carer—about things like nutrition and fluids; fundamental things like that. These are not just isolated cases; there are too many of them. How do you see this Act in terms of advocacy from close relatives and carers? Is the balance right?

Professor Richard Jones: In the situation you described, the clinician has to take into account the views of the parent. The parent cannot determine the course of action that is to be taken from a medical perspective. A parent, because of their role, will advocate what they believe to be best for the child. I do not think that that needs to be given statutory form. It is what parents do.

Baroness Browning: But parents are told that once their child is over the age of 18, their views and concerns are overtaken by the view—or failure to express a view—of the newly adult child. That is something that, in particular with learning disability, autism and some chronic mental health conditions, has led to some of these tragic cases.

Professor Richard Jones: That is assuming that the patient who is an adult has capacity.

Nicola Mackintosh: I think that it depends in many cases on the outcome. I have lots of clients who are being cared for by their parents, and the parents are saying, “We are unable to cope any more, please can we work with the local authority to find a long-term residential placement where we can still have lots of contact with our loved one”, but the local authority is not listening—because it suits the authority, to be frank. So in the situation where a parent is in hospital, standing by the bedside of their loved one, it depends on what suits the professionals a lot of the time. That is the difficulty.

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That is not to say that there are not disputes. There are very hotly contested disputes—I can speak from great experience. In cases that come before the Court of Protection, there is often a big clash between the family and the professionals. One thing that I try to do in my cases is mediate a solution. A lot of the time there is a misunderstanding and a clash between the family and professionals, and there needs to be more dialogue to resolve that.

Q40 The Chairman: The next issue has already been touched on. Ms Mackintosh and Ms Keywood referred to the need for understanding of the Act by people who are involved in it. Perhaps I could ask a question in particular of the Law Society, because Ms Mackintosh is speaking on behalf of the Law Society as well. I appreciate that you have a special practice, but what about a solicitor who has a general practice and is not a specialist? What steps does the Law Society take to ensure that members of the profession are aware of the Act and also know how to operate it?

Nicola Mackintosh: There is always room for improvement. However, we at the Law Society issue practice notes to guide the profession on a number of issues. One practice note is in relation to representation before a mental health tribunal. That can also include issues such as the duties of solicitors to their clients in that setting, where the clients may lack capacity. It is a double complication. We have been talking about whether there is scope for issuing a general practice note to the profession on the Mental Capacity Act. We have issued a financial abuse practice note, alerting legal practitioners to the risk of financial abuse of vulnerable clients. I think that that has gone quite a long way to improving the knowledge of the legal profession. No decision has been made yet, but the difficulty with the general mental capacity practice note is in the title. In issuing a general note, one always approximates and summarises. One cannot provide for every situation. It is a very difficult balance. One has to decide whether to issue a general note and general training, or more specific and directed training.

The Chairman: Are practice notes by the Law Society any more effective than statutory codes of practice?

Nicola Mackintosh: No, they are no replacement at all. But in answer to your question about what steps the Law Society is taking in relation to its members, that is some work that we have already done and that is ongoing.

The Chairman: What I am trying to get at is the extent to which solicitors or lawyers in a general practice are aware of the Act.

Nicola Mackintosh: I think that there is great room for improvement. The problem is potentially also because of the way that cases are funded. Most of my casework is funded through legal aid because, by definition, my clients are very poor. Those lawyers who are not undertaking legal aid work may be less familiar with the types of cases and legal issues raised by representing vulnerable clients.

Q41 Lord Faulks: I should begin by declaring an interest as a practising barrister with some experience of mental capacity issues. Following up on the question of the Lord Chairman, on the question of mental capacity generally and the test for it, I appreciate what Professor Jones said about it not being easy. Today's *Times* reports that the Court of Appeal decided that Mr Justice Hedley in the Court of Protection had got the test wrong. There were particular facts; I will not weary the Committee with them. However, that is an example of a judge with experience in the Court of Protection getting the test wrong. I wonder, looking again at the statute with the elegant solution that it provided, whether the

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test is too difficult, given the myriad circumstances to which it will have to be applied, and whether we should simplify it.

Kirsty Keywood: One way in which we could and should simplify it to some extent—I am not sure that this will satisfy you—is to get rid of the diagnostic thresholds. That is to say, currently under the legislation you have to have an impairment or a disturbance in the functioning of the mind or brain before you can be found to lack capacity by struggling with one of the other decision-making elements of the test. I think that that has to go. It is in breach of the UN Convention and it is also incredibly difficult to know exactly what is at the source of somebody's struggle to understand, weigh up, retain or communicate information. So that is one area where I would certainly suggest that we modify the test of capacity. I have come across lots of people who did not have an evident mental health problem or a learning disability yet who struggled to make decisions because of the very complicated circumstances in which they lived their lives. The current framing of the mental capacity test hinders the ability of some services to provide imaginative, effective support to those individuals.

Professor Richard Jones: The task you are setting us is extremely difficult. One of the benefits of the current test, which as you know is issue-specific in the sense that somebody may be mentally capable of making decision A but not decision B, is that it allows somebody to use their maximum decision-making capability. If you simplify the test to make it more general, it will have the consequence of denying some people who could make certain decisions the power to make them. So the test is the correct one, but it just gives rise to such difficulties in practice. This goes back to what I said in my opening remarks. The Act is just ignored for most decisions. It would be a practical impossibility for all these assessments and best-interests judgments to be made for the dozens of decisions that are made in respect of a person in the course of a day. I would be against losing the central component of empowerment that the Act currently provides.

Lord Faulks: I would like to ask about the Court of Protection. It existed before but was given a vastly enlarged jurisdiction. Clearly, it will take some time for any court to settle down. In so far as case law has emerged, do you think that the court is getting it right? Is case law proving the worth of the Act or the contrary?

Katie Johnston: I will talk about one particular line of case law. The problem with DOLS is that they are not used sufficiently. One of the problems is implementation and lack of training. Another big problem is that there is a serious lack of clarity in the definition of deprivation of liberty. This is partly structural. The Act does not provide its own statutory definition. It ties it to Article 5 of the convention. That is obviously problematic in itself because it is a constantly changing object. That then flows into domestic practice. Domestic case law is constantly changing. I have been at training sessions where social workers who are not legally trained are shown extracts from judgments of the Court of Appeal on a whiteboard and told to apply them in practice. That is obviously very difficult. So the fact that it is tied to case law is difficult in itself.

The case law of the Court of Protection has been quite lacking in how it has interpreted deprivation. DOLS are not being applied as it is. But the court has narrowed the definition of deprivation of liberty so that many people who are undoubtedly detained in the sense of Article 5 of the convention fall outside the scope of DOLS. In particular, I am sure that you are familiar with the Cheshire West judgement, which is coming through the Supreme Court. It develops an unfortunate test of normality where, essentially, a disabled person would not be deprived of their liberty if the restriction that they are subject to is something

that could be expected of somebody with similar disabilities—I am paraphrasing. This is obviously completely unacceptable. It narrows the scope unacceptably and turns human rights on their head. Human rights are universal. Everybody is entitled to the same protections, and if there are restrictions, they have to be justified. So we think that a statutory definition of deprivation of liberty that is not tied to Strasbourg would be a real help in increasing certainty.

The other restriction that the court has developed in its case law has been the return of the idea of reasons as going to the issue of whether there is a deprivation. This appeared in Strasbourg case law in the past but the court resiled from it. Now it has made a reappearance in the British courts. The idea is that the reason for the detention can affect the question of whether there is a deprivation in the first place. Again, that turns protection on its head. If there is a deprivation, you look at the reasons to see whether it is justified and proportionate. Those are the two big problems in deprivation case law that a broad and clear statutory definition that is freestanding would help to address.

Q42 The Chairman: Ms Keywood?

Kirsty Keywood: I think that the definition of what a deprivation of liberty is does not show the Court of Protection at its best. But in fairness, the jurisprudence and the legislation that it has to work with did not give it much to go on. With such exceptions, I have been incredibly impressed by the judges in the Court of Protection. I have been very heartened that they have given rulings and declarations with great humanity and compassion for the people and families whom they are supporting. When I think about the Court of Protection, one case that always springs to mind is that of Steven Neary, and Mr Neary's valiant efforts to scrutinise and challenge the circumstances surrounding his son's deprivation. The judges have been remarkable in their ability to communicate some very complex and difficult issues to an audience that goes beyond the person lacking capacity and their family, including wider communities that have been quite anguished about some of these things. Lord Justice Munby said that the Court of Protection offers a Rolls-Royce service. That is absolutely right. The difficulty for me is that it comes with a Rolls-Royce price tag that many local authorities cannot afford.

Nicola Mackintosh: It is important to remind ourselves of the breadth of cases that come before the Court of Protection. There are very few DOLS cases at the moment. I agree that the line of judgments on what is a deprivation of liberty has been extremely unhelpful to everybody applying the Act on the ground, and also to all those people who in my view remain detained in hospital without any protections. But there is also a wide range of cases that concern other issues such as where somebody should live. That is not an easy question at all, particularly if the issue is whether they should live with their family or in care, which is the most common scenario. Issues around contact with relatives, especially where there may have been a history of abuse, are complicated. Issues of forced marriage, removal from a jurisdiction and capacity to consent to sexual relations all come before the court.

The court works well in many cases, even though only a tiny proportion of disputes come before it. One of the major issues that I have is that where there is a serious dispute about a serious issue, whose responsibility is it to place it before the court? That is unclear. For example, if a statutory organisation is purporting to make a decision on behalf of an incapacitated person where there is a clear dispute about a serious issue, in my view that statutory body has and should have the responsibility for placing that dispute before the court for determination. In my experience, what happens is that the statutory body just goes ahead and makes the decision, and leaves it either to an advocate, if the person is lucky

enough to have one, or to some other person, to bring the case before the court. Often that simply does not happen. So that is a serious shortcoming that could be plugged.

The court definitely could be improved. It is more expensive and unwieldy than it needs to be. I could make a number of practical suggestions that would help. There should be very prompt access to a suitable litigation friend for the incapacitated person. We are all aware of the difficulties that the Official Solicitor's Office has had in relation to providing the services of a litigation friend in some cases—it is now operating a waiting list—because of a lack of resources. The minute you have a waiting list for a litigation friend, or you do not have prompt access to a suitable litigation friend, the case comes to a halt. That is in no one's interests. If we had very tight case management, with cases allocated to individual judges who run the case from the beginning to the end wherever practically possible, that would make great sense. We should take out the plethora of court hearings that we have. Every time you have a court hearing, you are incurring enormous expense and raising the expectations of relatives that this will be a final decision and a final hearing. Wherever possible, try to reach an agreement on the papers that is then placed before the allocated judge. There may not be a need for a hearing at all until the final hearing to determine the underlying dispute. There may be room for a practice direction to streamline the court process, which may reduce the costs and make the court more accessible. The court needs to be much more flexible. I talked about the judge who visited my client in the care home. That made all the difference. The courts need to go to where the person and the family are. We should not have a situation where everybody has to travel very large distances to turn up for a hearing that starts at 10.30 am, only to still be waiting at 4 pm and maybe not even to go before a judge. That is not acceptable. Sometimes things go wrong, but often the whole structure of the court process can be streamlined so that the focus is on the incapacitated person and their family, on the time that the professionals are taking in attending court, and on the entire cost of the process.

Q43 Lord Faulks: Perhaps I can ask you about the way the court does not always work satisfactorily. I base this on a number of solicitors who have spoken to me, and on articles in the press quoting judges. I am referring in particular to the out-of-hours provisions. The court has to be available at all times and in any place. That is a great aspiration, of course, but there is a suggestion that local authorities are often using the out-of-hours service inappropriately and making applications as a matter of urgency for judges—one of whom was at the zoo, I believe—to make a particular order. Mr Justice Hedley said, "There are very few cases which can't wait until Monday morning". In your experience, when you are talking about serious decisions that must be taken, is there a danger that some of them are being taken out of hours when they should not be?

Professor Richard Jones: I have never come across that.

Nicola Mackintosh: My experience is that Mr Justice Hedley's comments have been largely taken to heart. I cannot speak for every local authority—there may well be cases that fall outside that clear guidance—but certainly I have not come across the inappropriate use of the out-of-hours service.

Lord Faulks: I am glad to hear it. The other question I want to ask is about legal aid. We heard from the officials that there was absolutely no problem with legal aid, and that despite the LASPO Bill and the consultation, legal aid would be available as before. I dare say that at least one of you may have some comments on that. Is there any difficulty in getting legal aid for necessary and relevant applications to the Court of Protection?

Nicola Mackintosh: The short answer is yes, but it is a little more complicated than that. There is a dearth of expertise in this area. As I said, most—though not all—cases are funded by legal aid. Legal aid is available, but it is limited. One of the categories of case for which it is not available in the Court of Protection is where a vulnerable, incapacitated person is being psychologically abused. Physical abuse is included but psychological abuse is not. Only one-third of Article 8 situations are included. For example, residence or a change of accommodation is not included. In practice, when one is faced with a disputed decision about a change of accommodation, it may also involve contact disputes and the deprivation of liberty. It may involve issues of physical abuse. Therefore, the person is caught—and entitled to legal aid—through those other headings. But it is quite strange that those two headings are excluded from LASPO, which mirrors what happened before.

The other thing is that legal aid is means tested. LASPO introduced new, much more stringent means tests. Previously, if the person was claiming what are called passported benefits such as income support or guaranteed state pension credit, they were, subject to a merits test, automatically entitled to legal aid on the basis of means. That has now changed. With LASPO, the new eligibility regulations effectively passport a person on income but not on capital. For example, if the person has more than £3,000, a contribution will have to be made until such time as their savings fall below that limit. There is also the latest *Transforming Legal Aid* consultation paper, which was issued only seven or eight days after LASPO was implemented. It includes a proposal for a new residence test. In order to qualify for legal aid, every single person will have to prove to a legal adviser that they have been lawfully in the UK for at least a year. It is difficult enough for us to act for mentally incapacitated persons who do not have ready access to files of their bank statements that we need to show to the Legal Aid Agency to prove that they are eligible. It is difficult enough to obtain that evidence, but trying to obtain evidence that somebody has been lawfully here for a period of at least 12 months in order to qualify for legal aid is going to be impossible. It will actively provide a complete barrier to access to legal aid for many if not all vulnerable people.

Deprivation of liberty cases are non-means tested as long as the deprivation of liberty issue before the court is a Section 21A application. Many cases start off as a challenge to a deprivation of liberty, whereupon the court authorises the deprivation of liberty. At that point, under Section 16 of the Act, the person moves from a non-means tested system to being means tested. So in practice many people are excluded. We know that very few Section 21A applications come before the court. In the vast majority of cases that come before the Court of Protection, people may be eligible for legal aid, subject to their means, but if they have even a small level of capital, they will not be eligible. So things are very different to how they were before 1 April. That is the short answer.

Katie Johnston: Perhaps I could add one thing. I agree with everything Ms Mackintosh said. This area of law highlights another problem with transforming legal aid, which is the removal of a client's choice of solicitor. Obviously, mental health law is an incredibly specialised area of law. If the proposals are implemented, legal aid clients will have absolutely no choice of who their solicitor is. If you do not get a solicitor who specialises, for example, in this area of law, it will affect your ability to make an arguable, plausible case and have it executed correctly.

Nicola Mackintosh: Could I make one additional comment? One of the Government's proposals just over a year ago, which may well come back, was to channel all potentially legally aided clients through the telephone gateway. We made very strong representations against that, because we felt that it discriminated against people who might find it difficult to

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communicate over the telephone, who might not be able to use a telephone or who might not have access to a telephone. These cases are funded either under a community care legal aid contract or under a mental health legal aid contract. If the Government's promise to roll out all areas of law into the telephone gateway is implemented, it will act as an effective barrier in all areas of law for anybody with difficulties using a telephone, which will include people in mental capacity cases.

Q44 Baroness Barker: I will wind up with the Office of the Public Guardian, and LPAs. The intention with the Office of the Public Guardian was that abuse would be protected against by the use of Court of Protection visitors. Has that worked out in practice?

Professor Richard Jones: I have not come across a case where there has been a problem getting a Court of Protection visitor, but I know that there are very few of them. Certainly it has not come on to my radar.

Nicola Mackintosh: My expertise is in health and welfare cases, although in almost all cases, even where the incapacitated person is in receipt of benefits, there is some level of abuse by family members. To what extent the Court of Protection visitor service assists with that I do not know.

Baroness Barker: Who would know? Where would it come up?

Nicola Mackintosh: As I said, all the cases that I have dealt with involve some abuse. Perhaps local authority money-management departments—those that still exist—might be well placed to comment on that. So might charities. My experience is that the use of appointeeships is patchy. We pick it up in health and welfare cases and try to deal with both sides.

Baroness Barker: To be fair, appointeeship was patchy before the Act. Is the registering of LPAs understood? Are they being taken out as widely as we anticipated? Last week we were given some figures. I will not quote them, but we got the cumulative figures for the time since the Act came into force.

Professor Richard Jones: My impression is that they are being used by the same people who used the enduring power of attorney option under the old legislation. I hear lots of cries of concern that applications are being sent back to people because of some minor error in the form. That appears to be a problem. This goes back to some of the points that were raised at the beginning of our session this morning. It is a question of knowledge. Do people know that the option to make an LPA exists? The knowledge is certainly there among the middle classes, but whether it goes wider than that I am not sure.

Baroness Barker: Are professionals in memory clinics, for example, raising awareness of LPAs?

Professor Richard Jones: I just do not know. Perhaps, if the memory clinic is being used, you are getting to the end of the timeframe when there is an option to execute an LPA.

Baroness Barker: That is a fair point. At the time the legislation went through, some of us predicted that the cost would be prohibitive. Was that worry right?

Professor Richard Jones: I do not think that it is prohibitive, but certainly it is a disincentive.

Nicola Mackintosh: I think that the forms could be simplified. I am all for simplification and removing all duplication.

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Baroness Barker: The forms are enormous.

The Chairman: Have you given any thought to what the forms should contain—both the earlier forms you mentioned and these forms?

Nicola Mackintosh: I could have a bash. It would be a very initial bash, but I could have a try. And it will not be perfect.

The Chairman: It would be a useful start. Thank you very much to all of you. We are very grateful for the time you have given us. It has been a very useful and interesting session.

Toby Williamson and Sue Brown, Dr Pauline Heslop and Dr Margaret Flynn – Oral evidence (QQ 45-73)

Evidence Session No.3

Heard in Public

Questions 45 - 73

TUESDAY 2 JULY 2013

Members present

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

Witnesses

Toby Williamson, Head of Development and Later Life, Mental Health Foundation, former Co-Chair of the Making Decisions Alliance, and **Sue Brown**, Head of Public Policy, Sense, former Member of the Making Decisions Alliance

Q45 The Chairman: Good morning. I would like to welcome both of you to this evidence session. I am sorry that we have kept you waiting slightly longer than we anticipated. We are anxious to have your evidence today. You will be aware that the call for evidence has been sent out; although this evidence session will be an opportunity for you to explain things in some detail, if you wish to add anything that you do not feel you have covered adequately, or even if you simply wish to respond to the call for evidence, we would be very pleased to receive that. I am sure that it would be very helpful for us. I will start by asking about your involvement with the pre-legislative scrutiny. First, what was the purpose of the Making Decisions Alliance and how was it formed? Going on from that, could you say something about your experience of contributing to the pre-legislative scrutiny and indicate whether there were any things that you feel might have been done better?

Toby Williamson: I will start. Good morning and thank you, Lord Chairman. I co-chaired the Making Decisions Alliance from 2004. The alliance had been formed in 2002 to campaign in support of the introduction of mental capacity legislation in England and Wales. It was formed of about 40 national and regional charities that worked with different groups of

people with disabilities; the Mental Health Foundation was one of those, as was Mind, Rethink, Mencap, Sense, Age UK and the Alzheimer's Society. When legislation was introduced by government, firstly through the pre-legislative scrutiny process and then into Parliament in 2004, we worked closely with government, both the Department of Health and the Lord Chancellor's Department as was—obviously now the Ministry of Justice—working in collaboration with and support of government for the legislation to be passed. It felt like quite a positive process, from the Making Decisions Alliance point of view, that we both had the same objectives to ensure that good mental capacity legislation was introduced. We worked throughout the parliamentary passage of the Bill to support it. It had a bit of a rough ride at times, because at times there were accusations that it was allowing euthanasia by the back door, and various other aspects that we certainly did not agree with or support, but that required us to do quite a lot of lobbying and support work with government to ensure that it was passed. We were particularly keen that advocacy should be introduced within the legislation, that there should be principles at the beginning of the legislation, that decisions to refuse treatment should be within the legislation, and that there should be an emphasis on non-discrimination in the way capacity was assessed and best interests were determined. So there were a number of features within the Bill that was eventually passed which we were very pleased with.

Although the Making Decisions Alliance ceased to exist after the Bill was passed and the Act came into effect, our view as an organisation—and that of many organisations I still have contact with who were members of the MDA—is that it remains a very positive and progressive piece of legislation that has benefited large numbers of people who may lack capacity through both empowering them to make decisions themselves and protecting them if decisions need to be made on their behalf, and that it provides greater legal clarity for carers and practitioners working with them. Unfortunately, as you may have heard from previous witnesses, there still remains a challenge in terms of ensuring that it is properly implemented and understood across all sectors that need to apply it in practice; particularly the health and social care sector, statutory and non-statutory services, but other sectors as well. There are a number of aspects of the Act which seem to cause difficulty in some areas, particularly, for instance, care homes and general hospitals, in terms of its application. It is much better understood within specialist services for people with learning disabilities and dementia, for example. So there is still work to be done in ensuring that it is properly implemented. But our view, and the view of other organisations that were members of the Making Decisions Alliance, is that the priority is to ensure that it is properly understood and that there is proper awareness across sectors for what is still a relatively young piece of legislation, rather than place any priority on reform of the legislation at this stage. It is still too early to do that. We are currently working with a number of organisations, including government departments, to try to develop a cross-sector collaborative approach to raise awareness and improve understanding across professional disciplines and different aspects of the health and care sector, to improve that awareness and understanding as a priority rather than focusing on legal reform.

Q46 The Chairman: Thank you very much for that helpful outline. I should have said before we started that you will be aware that the evidence is being recorded by shorthand writers and is also being broadcast. You will be given an opportunity to see a transcript of the evidence and to alter or rather correct it if there are any obvious mistakes. Do you want to add anything, Ms Brown?

Sue Brown: I should briefly explain what Sense's role in the alliance was, and briefly our experience and interest. Sense is an organisation that works with deafblind people—people with both a hearing and a sight loss. We have two interests in this legislation, which was

extremely important to us. We support a number of people who were born deafblind, who can both lack capacity in a lot of areas of their life, but one of the common issues about people who are deafblind, whether born deafblind or those who have acquired deafblindness, is communication and the need for support with communication. We have a number of areas of interest in this. The first one is people who lack capacity to make particular decisions and how they are supported and protected through that process of someone making that decision in their best interests. The second is people who maybe are assumed to lack capacity because they struggle with communication, and without the right communication support will be thought to lack capacity when actually they do not; and thirdly, ensuring that people who need communication support are supported through the decision-making process, whether that is them making their own decision or being involved in a best-interests decision-making process. So that is our interest. I echo what Toby has said about the way in which the alliance worked and the fact that Sense certainly feels that the legislation itself is a really good framework for supporting our staff when they are working with people in those different situations. The problem is when they are working with professionals who maybe have less awareness and understanding of the Act than perhaps they should.

The Chairman: Does Sense provide interpreters, then, who assist professionals to assess capacity? Presumably there is a communication issue between the person who is deaf and blind and the doctor or whoever is trying to assess capacity.

Sue Brown: Yes. In some cases somebody might be, for instance, a sign language user, and a sign language interpreter would be able to interpret for that person. A lot of the people we represent have quite profound and complex needs; they may have very limited language or no formal language at all but are very able to communicate provided that they have the support of someone who understands how they communicate and understand things. That can be where we have the biggest problems, when professionals do not see that what the person is doing is communicating; sometimes they are communicating very clear choices, but the way in which those choices are expressed is not in formal language so it can be quite difficult to understand. We might do a range of things, from making sure that a medical professional has booked an appropriate interpreter through to assisting a professional to understand somebody's complex and informal methods of communication.

Q47 Baroness Browning: Lord Chairman, I should first remind the Committee of my interests. I am a vice-president of two of the national charities that were part of the Making Decisions Alliance. Going back to the submission you made to the Mental Capacity Bill at the time, you indicated an overall desire that people of marginal capacity should be supported to reach capable decisions—I think we sometimes referred to marginal capacity as fluctuating capacity in the passage of the Bill—and of course that people without capacity should be involved as much as possible. Could you just give us a feel for how those two separate groups have fared under this legislation? Clearly there is quite a spectrum of decision-making, from perhaps what an in-patient wears as opposed to somebody telling them what they are going to wear when they get dressed for the day, to perhaps more serious matters such as where they are going to live in future. Can you desegregate how those two groups have fared?

Toby Williamson: Perhaps I can start and then I am sure Sue can add something to this. I should have said at the beginning that the Mental Health Foundation is a social research and development charity. We undertake work on issues that affect people with learning disabilities, dementia and mental health problems. In 2012 we published a large piece of research that was funded by the Department of Health, which we carried out with the

universities of Bristol and Bradford. It looked at best-interests decision-making for people in all those groups and revealed a number of findings. First, as I have already said, in some sectors—general hospitals and care homes—there was much less familiarity with the Mental Capacity Act and they struggled with people with fluctuating capacity. We were very pleased when the Bill was passed that it had a very decision-specific and time-specific emphasis around decisions, so people could not be assessed as lacking capacity to make any decisions but had that decision-specific nature to it. While the principles were the correct ones, the findings from research indicated that a number of sectors or services and professionals struggled to understand how actually to implement the Act in relation to people with fluctuating capacity. The findings from the research indicated that the process was quite effectively followed around assessing capacity and making best-interests decisions around big decisions such as consents on medical treatment or changes in accommodation, but there was very little report made on those everyday decisions that you describe. There was perhaps a sense that a similar practice that occurred before the Bill was passed is continuing, in that there may well still be assumptions of incapacity based upon diagnosis or a disability.

The research also indicated that staff—in particular health and social care staff—struggle to apply or link the principles around assumption of capacity and wise decisions to actual practice. They said, “We think that the person has capacity, therefore we will just let them make their own decisions”. There is an example of a lady in a care home who had significant dementia, who was refusing to change her clothes at all and was becoming quite soiled, and staff were not sure what to do. They had been led to believe that they must allow people to have autonomy and make decisions themselves, and did not understand that they could use the Mental Capacity Act to assess capacity and potentially intervene to improve the person’s quality of life by making decisions for the person if they lacked that capacity. So there was an issue there around the principles not being very well linked with the actual practice. When the process was being followed around involving people in best-interests decisions and in assessments of capacity, the evidence that we gathered from research anecdotally indicated that staff can follow that process quite well. In over or around 50% of the best-interests decisions that were made, it was reported that the person who lacked capacity was involved in some shape or form in helping to direct that decision, even if they could not make the decision themselves. So staff understand process better than they understand the principles or application of the principles.

The Chairman: Mr Williamson, I am sorry to interrupt. I know that there is a lot in what you are saying, but would it be possible to give the Committee a copy of this report? That might be very helpful.

Toby Williamson: Yes, of course.

Q48 Baroness Browning: Yes, that would be very helpful. Does it include how eligible both those groups were to advocacy when they needed it?

Toby Williamson: A number of independent mental capacity advocates were involved in the research, so it focused specifically on the role of the IMCAs—the independent mental capacity advocates. It did not go beyond that and investigate whether other advocates were being involved in decisions. As I am sure you are aware, the IMCA service is limited to very specific decisions and for people who do not have friends or family with whom it is appropriate to consult. What was quite interesting and significant, and I think reflected previous research into the IMCA role, was that IMCAs were often getting drawn into situations in which there were disputes about a best-interests decision, assisting in resolving those disputes and playing a key role in supporting all parties in coming to a good best-

interests decision where there might have been disagreements. However, they were also involved in cases where family and friends of the person who lacked capacity were there. Previous research had shown that IMCAs were been drawn into those situations as well. Indeed, when we were campaigning in support of advocacy to be included within the Act, our view was that IMCAs should be made available to people who had family and friends where disputes arose, because many families would be very unfamiliar with complex health and social care systems, and therefore would be at a disadvantage if there were to be a dispute with a very knowledgeable social worker or doctor. Having advocacy to support them would therefore be very helpful. The research seems to indicate that IMCAs were getting drawn into those situations, but generally in a very helpful way. So to extend advocacy in that way could potentially be very useful.

Sue Brown: Just to follow on from that, we tend to find that first of all, our staff say that the people with the best understanding of the Mental Capacity Act and how it should operate tend to be front-line social workers. They find many more issues within health, and particularly within primary healthcare. GPs and dentists were the two groups that were highlighted as those who our staff had the greatest issues with on whether they were actually following the Act. One of the things that they report is that it can be easier and quicker; there tends to be an immediate assumption of lack of capacity and then they go straight into saying, “We’ll make this decision in the person’s best interests”. Rather than taking the time to explain to someone what needs to be done and getting their consent, in the case of dentists it is often, “Can we sedate this person so that we can treat them without needing their consent?”, or GPs saying, “Well, it’s in their best interests to take the blood, so we’ll just take it”. They do not take the time either to check that they understand and get consent—in a lot of cases people might understand—or even to involve them in the process and explain to them what is going to happen.

We also find that the less formal communication you have, the more likely you are to be assumed to lack capacity, without a proper capacity assessment having taken place. The feeling of our staff is that some of that is to do with lack of understanding around communication issues. Some of it may be to do with time. I have had one report of a GP who attempted to charge for the additional time taken to explain to the person what was involved in a blood test and get their consent rather than simply do a best-interests decision. So there is an issue around time, which may be why things are better in in-patient general hospitals, where there is a little more time. That is certainly the experience of our staff. There is definitely a connection with communication. There is a real issue with people understanding informal and limited communication as being someone still having the capacity to understand, and that they just communicate in a different way. Our staff say that they often have to guide other professionals through the process. They find the Act a really useful framework to be able to say, “No, this is how it is supposed to work”. But often, again, medical practitioners do not want to take that role of decision-maker and make a best-interests decision; they attempt to get our staff to consent on behalf of people, which is clearly not in line with the Act at all. I would say that there is generally a lack of understanding of the Act, but that it is a really useful framework for our staff to be able to say, “This is how it should work”; and there are the particular problems around communication.

The Chairman: We have to make progress. I wonder if it is possible in future answers to try to keep them fairly short, because we have got quite a lot of material to get through. As I said earlier, it is always possible to supplement evidence in writing.

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Q49 Lord Patel of Bradford: I will focus on the deprivation of liberty safeguards. As you will be aware, the Joint Committee on the draft Incapacity Bill, as it was known then, predated the deprivation of liberty safeguards. Did the Making Decisions Alliance form a view of the DOLS during the passage of the Mental Health Bill? We have had some very opposing and varied views on the best use of DOLS.

Toby Williamson: This can be a shorter answer. The Making Decisions Alliance was coming to an end when the Bournemouth case was announced and thoughts and plans were being made about how to address the so-called Bournemouth gap. We recognised that a legislative solution had to be found to address that. We wanted a relatively simple legislative solution that met the requirements of the European court's findings on the case, something that reflected the elegant simplicity of the Mental Capacity Act. What has happened is rather more complex, quite bureaucratic and difficult to understand, and it is much more procedurally driven—I am describing the current deprivation of liberty safeguards. Of course, they were led by the Department of Health at the time when it was also dealing with the reform of the Mental Health Act. So they have a very strong flavour of the procedure of the Mental Health Act rather than the simplicity of the Mental Capacity Act. We recognise that there is some research going on, both at the universities of Cambridge and Bristol, which is looking at the interface between the Mental Health Act and the Mental Capacity Act, and looking in particular at DOLS. Until that research is published I would not have much to comment, other than that the research we did—the best-interests research—reported that sometimes interventions were used which might have constituted a deprivation of liberty, but that there had not been an application made for deprivation of liberty because staff did not seem to understand or were rather concerned about what that might involve. This is one bit of the Mental Capacity Act where from our point of view the jury is out in terms of whether this should be changed or allowed to bed-in further. However, it is certainly proving challenging for many people who are affected by it, whether staff, service-users or families.

Lord Patel of Bradford: Do you have a timescale on the research?

Toby Williamson: As far as I know, the Bristol research that is looking at DOLS is due to be published this calendar year. I do not know about the Cambridge research; I thought it was due to be published last year but it has not been yet, so I do not know.

Lord Patel of Bradford: It would be useful to get it.

The Chairman: I was going to ask that as well. Do you know who is doing the research?

Toby Williamson: It is led by Professor Tony Holland and Isabel Clare at Cambridge University—that is on the interface between the Mental Health Act and the Mental Capacity Act. The DOLS research at the University of Bristol is based at the Norah Fry Research Centre. I only know the name of the research assistant involved; I am not sure who the principal investigator is. The Norah Fry Research Centre will be able to tell you.

Q50 Baroness Andrews: Can I ask you to go back to the implementation of the Act? In your submission on the pre-legislative scrutiny you had concerns about the scope of the general authority. You tried to address that by suggesting at the time that various conditions were attached to the way that that should operate in terms of case conferences and additional safeguards around the general presumption of capacity. Do you think you were right, and do you regret that those changes were not made? Do you think that they would

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have made a difference to the way the Act is operating, particularly in light of what you said about the presumption of a lack of capacity?

Toby Williamson: Obviously the general authority was changed and is now known as the acts in connection with care and treatment. That was a helpful change, because it emphasised the focus on decision-specific and time-specific capacity assessments and decision-making rather than the general authority, which applied a general power to act on behalf of people who lack capacity. Again, the research we carried out showed that in around 25% of cases involving a best-interests decision, the capacity assessment that led to the best-interests decision was based on looking at the person's disability, diagnosis, age, appearance, condition or an unwise decision, which rather leads us to believe that, certainly in a number of those cases, people were still making assumptions about a lack of capacity for reasons which the Act does not allow, i.e. a blanket assumption based upon diagnosis or an unwise decision. That gives some cause for concern that safeguards are still not properly understood and that the process is not properly understood in terms of applying the principles to the acts in connection with care and treatment. The other thing is that the findings from the research show that in many cases complex decisions involve multi-disciplinary teams, so staff were struggling to understand who a decision-maker is and what is the exact decision that was being made. In 10% of the cases that were reported, people reported the decision as being a multiple decision, so again it was not decision-specific. We suspect that perhaps that was in certain situations; there were examples of situations in which someone was being prepared or was ready for hospital discharge and the decisions about medical treatment and accommodation issues were all being piled into one meeting, and staff were struggling to know who was the decision-maker and what different decisions they had to cover. In another 10% of cases it was reported that the person had capacity, even though a best-interests decision was being made on their behalf, which indicates a worrying lack of understanding of the legislation. This risk occurs once a lack of capacity has been found—and this may apply to DOLS as well, where people have severe dementia or a very severe learning disability and a range of decisions are being made on their behalf because it has been put in their notes that they lack capacity.

The Chairman: For the sake of the record, Ms Brown, I see that you were nodding agreement with what Mr Williamson was saying.

Sue Brown: Yes, particularly on the issue of complex decisions—not being clear who the decision-maker is in the meeting. Again, our staff report that if you have multi-agency meetings, no one agency is willing to say, “In the end, having consulted everyone, this is our decision”. That can be really difficult.

Q51 Baroness Andrews: In your first response to the Committee you said that you did not think that the law needed changing. You said that what you thought needed to happen was that practice needed to be improved, and that there was an issue about information and understanding. For example, on the absence of a key named person who should take a lead decision, is there any argument for changing definitions legally, or for changing the nature of responsibility legally? We are trying to understand how you can change the culture, and how effective any exhortation or information can be if you still have people untrained in processes—informal and so on. It is really difficult to get to that particular challenge.

Toby Williamson: My view is partly based on research in which a lot of staff reported that the Mental Capacity Act was a really positive piece of legislation that had helped to clarify decision-making processes for them in a number of situations. So where it was understood, no one was saying, “This is bad legislation”, and it was being properly implemented and

applied in a whole range of situations. I suppose that I would have some concern about having named people and named roles, because that feels rather like moving into something similar to the Mental Health Act, which is an important but a very different piece of legislation, with different aims and objectives. The Mental Capacity Act makes it quite clear that there needs to be a decision-maker who makes a best-interests decision if that is required. The emphasis should be on trying to ensure that how the Mental Capacity Act is applied is properly understood as underpinning a range of health and social care procedures that already exist.

We hear a lot about safeguarding and dignity and respect, we have the Prime Minister's Challenge on Dementia, we hear about choice and control and risk decision-making, and those are issues that are of considerable concern to people working in the health and social care sector. However, the Mental Capacity Act, when properly applied, underpins and helps decision-making in all those settings. If staff understand how the Mental Capacity Act works—and it is a simple piece of legislation, and many people are putting it into practice on a regular basis; it is not a very complex process to assess capacity or make best-interests decisions once one is familiar with the checklists and the assessment process—you can insert that and embed it within those other policies and procedures that staff have to work to. In particular, safeguarding is dominating the thoughts and practices of many staff at the moment. You can therefore ensure that the Mental Capacity Act underpins that and empowers people to make decisions wherever they can for themselves, but also provides good legal protection for themselves and for practitioners who make decisions on their behalf. So my priority at the moment would still be to try to ensure that all those affected by the Act understand how it relates to other policies and processes that they have to work to rather than saying that the Act should be changed at this stage.

Q52 The Chairman: Baroness Shephard, I think the witnesses have already referred to IMCAs; I do not know if you want to ask a further question.

Baroness Shephard of Northwold: I would like to ask Mr Williamson if he wants to add anything to the points he has already made about the effectiveness or otherwise of the IMCA service. Is the service providing a good voice for clients? Is the legal framework understood and is it properly applied? You have already referred to it—do you want to add anything?

Toby Williamson: I would say just that not only does it provides an essential service to people who lack capacity, but anecdotally, from conversations I have had with IMCAs, it can be said that it provides an essential service to service-providers and professionals, who may be unfamiliar with the Act, who can see the benefit of having an IMCA come in who can spend time with a person who lacks capacity to find out more about what their wishes, feelings, beliefs and values are. So it creates a much better decision-making process when IMCAs are involved, which broadly speaking, the professionals recognise and welcome.

Sue Brown: Coming back to communication, we have a particular issue around the ability to find an IMCA with the relevant communication skills. We have had IMCAs arriving to work with someone, who have no sign language and no interpreter, and therefore again, our staff have to remain involved to facilitate communication, which does not allow the person to communicate anything they might want to say about our service, for instance—because we are still in the room.

The Chairman: What would you advocate in that regard? Should advocates be trained in sign language or in special communications skills for those who are blind and deaf?

Sue Brown: Yes, I think that those who are commissioning IMCA services need to make sure that communication is part of the commissioning process, so that every IMCA service can provide someone who understands people with a range of different communication needs.

Q53 Baroness McIntosh of Hudnall: We come to the rather uncomfortable question of the power to restrain. The MDA indicated early on that it was anxious about the abuse of that power. It is pretty clear that at least in some cases it has been abused. If we look beyond the very high-profile examples of that abuse, do you have any views about whether your general discomfiture about the possibility of abuse has been more widely vindicated, or do you think that the power to restrain is being used in a more judicious way more widely?

Toby Williamson: I have very limited evidence or knowledge around this. We are not a service-provider organisation. Again, from the research that we did there was some indication that restraint was being used in a way that might indicate a deprivation of liberty, and deprivation of liberty safeguards had not been applied for, but we did not come across any examples of where restraint was being used in excessive or prolonged ways that indicated abuse by professionals. I do not know if you have anything to add to that.

Sue Brown: Our experience links back to the earlier question about the acts in connection with care and treatment. A decision is made that something is required, and in this case it might be restraint for the person's safety. Does that then get reviewed, or does it just become a routine part of the person's care that is not questioned? That can range from restraint to other issues. For example, we have recently used the Mental Capacity Act as a framework for reviewing all use of restraint within all of our services to ensure that we are not assuming that people lack capacity when they do not, to make sure that the circumstances that required restraint at the time still pertain, or whether the work that we have been doing for the person has altered their behaviour so that they no longer require restraint. In the case of our services, we are talking about things like additional harnesses when travelling and bed-rails; these are things that are clearly about the person's safety, but in our view you still need to review whether they are still appropriate, still in the person's best interest and still needed.

We find in a lot of services that that sort of review process does not happen. Someone may be restrained in a particular way in a particular circumstance for years and years without anybody going back and saying, "Does the situation still apply?" I think that that applied to restraint, but also generally to the way in which you support somebody. They were not able to make that decision, perhaps because of their learning disability, but if we have been working with them on their decision-making ability for a few years, maybe they are now able to make that decision for themselves, as they have developed communication and decision-making skills. So it is about that constant process of review—"Is this still appropriate?"—rather than about relying on a best-interests judgment that was made weeks, months or years previously.

Baroness McIntosh of Hudnall: Do you think that if you read carefully the Act as currently written, it tells you that you should be doing that, and that therefore this is an issue of implementation, or is the Act insufficiently clear about how that power should be used?

Sue Brown: I think that it is about implementation and about staff understanding. The Act is very clear that it is decision-specific and time-specific. That is clear; it is a matter of agencies having the review processes in place.

Q54 Baroness Barker: Hello again. Back then, when we all sat and listened to what you had to say and were duly impressed, I think it is fair to say that we all realised that lasting powers of attorney were going to be one of the key parts of this legislation as far as the general public and legal profession—as two key players in the whole process of looking after people who lack capacity in some respects—were concerned. Back then, there were concerns about people’s ability to set up powers of attorney and have them registered and activated. There was in particular a considerable concern that the cost would put people off. Now, in the wake of experience, what do you think about the provisions around LPAs?

Toby Williamson: Again, we have not got much evidence, either anecdotal or research-based, around LPAs. It is disappointing that there has been a very low uptake of health and personal welfare LPAs, because that was obviously a new part of the legislation which had not previously been available through the old EPA system. I suspect that cost and complexity—or rather perceived complexity—may have put some people off, although our understanding was always that LPA forms should be forms that could be completed by a lay person who did not require legal advice or a legal intervention. To a certain extent I think that the forms achieved that. There is some work that could be done to promote LPAs, particularly around health and personal welfare issues, although I understand that the OPG is seeing an exponential increase in LPA registration. So they are getting more into the zeitgeist, and people are more aware of them. Perhaps because we have an ageing population, and people are concerned about the growing number of people with dementia, more people are thinking about how they can plan for the future.

Baroness Barker: My last question is about the Court of Protection. A very key part of the alliance’s submission to us was that the Court of Protection should be accessible; it should be accessible to people with impaired capacity. How do you think that has worked out?

Toby Williamson: From what I recall, when we discussed with the department about the court as the Bill was going through Parliament, we were led to believe to a certain extent that the relatively informal nature of the Court of Protection which preceded the Act being passed would continue, and that things such as bedside hearings and informal communication with the court, which were seen to be a benefit, would still be available. Inevitably, as in many respects it acquired a different statutory status through the Act, it has become more formalised. From what we hear, people who may lack capacity, family members and people who are unused to the court system do not go to the court very frequently. They see it as something quite complex and sometimes intimidating, so there is a case to be considered for looking into whether disputes are occurring at a lower level and never actually reaching the court and being resolved through other means, whether that is through complaints procedures or mediation systems, and whether that could be more formalised and made more accessible and available to potentially divert the need for going through lengthy court cases or not getting disputes resolved in a very satisfactory way within health and social care settings. I am aware that possibly extending the IMCA service might help in that respect, and that in other jurisdictions—in the States and Australia—the role of the public guardian is to intervene and mediate in disputes, which is obviously not the role of our public guardian. I think that there is probably a need for further research to look at what kind of disputes are occurring, how they are being resolved or not, and to draw some conclusions from that before thinking about whether the court and those legal processes around resolving disagreements need to be changed.

Sue Brown: We have some concerns about the court’s ability to engage with people who have little or no formal language and instances where, as far as we are concerned, someone

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is communicating very clearly a decision and the court does not recognise that because they are not using formal language. There are some real issues about the court's understanding of the inter-relationship between communication and capacity.

The Chairman: Do you have any thoughts about how that could be improved? That problem exists; how would you go about instructing or educating the court about it?

Sue Brown: I think that it is clearly an education and training issue. It is an awareness issue rather than an inherent problem with the court, but it is one that we have come across.

Q55 Baroness Barker: If there was to be research on why people are not accessing the court in the way that was anticipated, who should we go and talk to about that? Is it front-line practitioners like people in memory clinics, or IMCAs, or who?

Toby Williamson: IMCAs would be a very good starting point, because as I said earlier, they often find themselves in situations where there are disagreements. There may be some people with fluctuating capacity, who have experienced disagreements with professionals about whether or not they can make decisions, and of course family carers may often be involved in disputes around best-interests decisions. In addition, practitioners may feel that it is not a satisfactory process around a care or health issue when there is a disagreement or dispute, and would welcome some further advice and being involved in research.

If I may, Lord Chairman, I will mention one other thing that we have not mentioned, which is about the code of practice. A number of the issues that we have discussed here, and indeed the recommendation from the research that we did, was that consideration should be given to revising the code of practice. I am aware that Department of Health officials were not necessarily of that view, and I recognise that that is a complex and costly process. We think that the code of practice is a very good document. It is very clearly written and very helpful, so we would not want to lose what is already there. Of course, however, it was drafted before the Act came into effect, so in a way it is a hypothetical set of descriptions and guidance, and now we are building up case law and evidence from research. Even if there was not the appetite for revising the code, perhaps consideration should be given, if possible, to issuing some kind of supplement to the code as an interim measure to gather together all the evidence that has been accumulated over the last six years since the Act came into force to provide that additional central point of reference and guidance that many practitioners would find useful. Perhaps that could go some way to addressing the concerns we have raised about awareness and understanding and show that the Department of Health, in working with other government departments, recognises the importance of the Mental Capacity Act as a piece of legislation that people really need to understand and be aware of more widely than currently is the case.

The Chairman: It would be useful if you could identify, obviously in written submission, any particular problems that you see with the code of practice and where it might be improved. That would be very useful for us to consider. Thank you very much for your evidence, which has been very useful indeed. As I said at the beginning, although you have given evidence we would encourage you to respond to our call for evidence. Thank you very much.

Witnesses

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 want 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 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 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

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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.²

Baroness McIntosh of Hudnall: Do you have a view about that?

² Dr Flynn added after the evidence session the following information: The CPS spoke of a “Disability Hate Crime” immediately after the trial.

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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.

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?

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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.

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

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that that 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 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

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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 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.

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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 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,

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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, 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

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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 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

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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 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.

Toby Williamson and Sue Brown, Dr Pauline Heslop and Dr Margaret Flynn – Oral evidence (QQ 45-73)

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 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.

Vanda Ridley, Beverley Dawkins OBE and Hannah Barnett, George McNamara, Peter McCabe and Paul Farmer – Oral evidence (QQ 74-105)

Evidence Session No. 4

Heard in Public

Questions 74 - 105

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

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, Beverley Dawkins OBE and Hannah Barnett, George McNamara, Peter McCabe and Paul Farmer – Oral evidence (QQ 74-105)

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?

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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.

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.

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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.

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

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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

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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.

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

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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—

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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 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

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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?

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

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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 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

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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.

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

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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?

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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 is 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

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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 Bournemouth 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.

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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

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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 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.

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?

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

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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

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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

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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

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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 Bournemouth 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 Bournemouth 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?

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

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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?

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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 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

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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.

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

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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.

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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.

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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.

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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

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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.

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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.