



# HOUSE OF LORDS

Unrevised transcript of evidence taken before

## **The Select Committee on the Mental Capacity Act 2005**

Inquiry on

### **THE MENTAL CAPACITY ACT 2005**

*Evidence Session No.3*

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*Questions 45 - 73*

**TUESDAY 2 JULY 2013**

**10.40 am**

Witnesses: Toby Williamson and Sue Brown

Dr Pauline Heslop and Dr Margaret Flynn

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### 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

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### 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 14 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 deaf-blind 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 deaf-blind, who can both lack capacity in a lot of areas of their life, but one of the common issues about people who are deaf-blind, whether born deaf-blind or those who have acquired deaf-blindness, 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.

**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 recognise 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 Nora Fry Research Centre. I only know the name of the research assistant involved; I am not sure who the principal investigator is. The Nora 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 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 lead 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 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-reading 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 and 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 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. The views of a third party, which were sometimes crucial to that decision-making process, had not been present at that best-interests meeting. 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 GPs. Thirdly, we 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 reviewed some training programmes and 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 was 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 people—at this hospital. We can confirm that these four people were objectively confined and that visiting to all patients at this hospital was very conspicuously restricted and became more so over time. The distress arising from the care regime within the hospital and that which was imposed, including the administration of medication and the use of physical restraint, was not 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, IMCAs,

hospital managers, second opinion doctors—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 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 has concerns that these patients have potentially been deprived of their liberty. Given that my colleague and I could find out no more 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 that have to be detained those periods of detention are for very 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 we do not know the capacity status of patients at the hospital.

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

**Dr Margaret Flynn:** I suppose I shared concern and disappointment that such fabulous legislation really had no impact whatever on the circumstances of the 51 former patients at Winterbourne View hospital.

**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 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 they 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 that were thinking about proactive planning for an individual, 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 we have. 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 ceased to be a manager and an acting person was in role, and there was even a period when there was no manager, things became very seriously adrift.

**Q61 Lord Patel of Bradford:** Dr Flynn, if I may I will take you back to Winterbourne View and the failings there, including the failure to apply the deprivation of liberty safeguards and this tendency to believe staff over patients constantly. Would you say that these were specific to Winterbourne View, or are there general lessons that have been learnt about the Mental Capacity Act and the deprivation of liberty safeguards?

**Dr Margaret Flynn:** I gather from conversations with relatives who have experience of assessment and treatment services elsewhere in the country that there are enormous concerns about the safety of their relatives when they are detained.

**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”—or 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 people 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 is 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 role of advocacy.

I am convinced that people desperately need independent assistance outside the hospitals. The hospital mediated access to advocacy; you had to go through one of the nurses, and if patients were troubled and distressed they were unlikely to go to 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 they 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 that up, and so no action was taken.

**Q62 The Chairman:** You mentioned about IMCAs being allocated through the hospital—that you had to go through the hospital to get an advocate. You were suggesting that that 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 that they should not be left there. The observation of the Mental Health Act Commission was that there was a sense that people had been abandoned at this hospital. So there should be frequent reviews, and during those and during monitoring meetings undertaken by staff associated with the commissioning of such places people should

be offered the opportunity to meet with somebody 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 understand 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 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, they believed that they were dealing with clinicians. We know that that conspicuously was not the case. However, that deference prevailed. When people were to be discharged, clinicians were sometimes instrumental in saying, for example, “I think it would be worth while retaining this person here for at least six months to work on his anxiety”—that is a real case from Winterbourne View hospital. The challenge that is endemic in best-interests assessment maybe 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 be 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 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, but 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.

**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 also substituting a former claim that the person has made a choice, as though that is irrevocable, immutable or long-term. I have certainly come across examples of older people who, in 1987, 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. The preoccupation has to be that he received the treatment that 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 not going to go to either the CQC or the local safeguarding personnel.

**Q67 Baroness Andrews:** In relation to Dr Heslop’s report, you actually made a whole raft of recommendations about improved relationships with the health service. We have referred to DNACPR. You talk about named healthcare co-ordinators, patient-held health

records, standardisation of health checks, access to specialist healthcare and specialist learning disability services. You have talked also about the fear of medical intervention, which presumably compounds this situation. Of those recommendations, which do you think actually would be most effective? Who should take the lead? Who should take responsibility?

**Dr Pauline Heslop:** Big question. I guess answering it in relation to your question, or directly in relation to the Mental Capacity Act—I am not quite sure I am answering your question—

**Baroness Andrews:** Ultimately, the MCA.

**Dr Pauline Heslop:** I would say we needed to be much better at identifying who people with learning disabilities are within the health service but, more importantly, we also need to be documenting the reasonable adjustments that they need to be able to access healthcare equitably, and we need to be auditing that the reasonable adjustments are being made. That will start us along the track of thinking about linking that in with the Mental Capacity Act, in terms of good decision-making for individuals once we know that there might be a need for that.

Related to the Mental Capacity Act, we did not find evidence of people setting out to deliberately harm an individual. What we found much more commonly was that judgments were being made about individuals and about the provision of care for those individuals which were not always optimal. They were not always fully recorded, so we could not clearly follow a decision-making trail. There are issues about that sub-optimal care. For example, a doctor watching and waiting just that little bit too long than was reasonable, or concoctions of medication that maybe had not been reviewed in a timely way—neither of the definitions of ill treatment or neglect within the Mental Capacity Act would, I suggest, cover those. But we did find that that general poor practice was a contributory factor to deaths.

**Baroness Andrews:** Could you recommend changes in the code of practice which would address some of this, in the context of looking again at the code?

**Dr Pauline Heslop:** Yes. I can certainly submit written evidence for you and neatly bundle together, if you like, our recommendations for the code of practice, if that would be helpful.

**The Chairman:** That would be very helpful indeed.

**Q68 Baroness Browning:** Could I just ask one quick question of Dr Heslop? In an earlier answer, you made reference to somebody with a learning disability who had inappropriately been put on an end-of-life care pathway? I just wonder whether, in your key recommendations, you felt there might be something to be said about people with learning disabilities and end-of-life care pathways? After a lot of pressure from the House of Lords, the Department of Health—I have to say, rather reluctantly, but it is now doing it—is reviewing the Liverpool care pathway, which is chaired by Baroness Neuberger. I did just wonder whether I could use this opportunity to say, if you have evidence of learning disabled people and their experience of the end-of-life care pathway, I think many of us would be very grateful if you would submit it to her inquiry.

**Dr Pauline Heslop:** One of the recommendations that we did make was that nobody should be put on an end-of-life care pathway without some referral to a palliative care service, as an additional check that that was an appropriate course of action for that person. So I hope that will go some way towards—

**Baroness Browning:** Thank you. We are very worried about people who have full capacity, let alone people without capacity.

**Q69 Baroness Shephard of Northwold:** The serious case review into Winterbourne View found that “light touch regulation did not work”. What implications do you think that finding has for regulation of the Act?

**Dr Margaret Flynn:** It did not work because the hospital was very good as presenting itself as a service that was next to none. Certainly, its documentation was very impressive-looking. We know that, with this binary of compliant or not compliant, it is easy to hit 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 visited. They spent about four days there. There were inspectors there 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 this.

It is not enough to check whether there are policies and things in place—the right number of bedrooms. 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 local services. 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 pain or whatever. 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 told about it. Neither was the CQC. The Health and Safety Executive took the view that, on the occasions they were informed of patients' injuries, they were not serious enough for them to undertake any investigation.

**The Chairman:** Dr Heslop, I think the question was addressed to both of you. If you have anything to add to that—

**Dr Pauline Heslop:** I can add in a very small way. Obviously, the confidential inquiry reviewed the individual circumstances of people's deaths. We did not review services, as it were. However, we did pick up on a number of issues that we would have expected a review of that service to have identified and required addressing—for example, a full

assessment of a person's needs, that a person was living in inadequate or inappropriate accommodation, poor record-keeping. In all those cases, the light-touch approach clearly does not seem to have worked.

**Q70 The Chairman:** Baroness Hollins cannot be here today, but she has asked me to ask both of you a question. What experience do either or both of you have of how the Care Quality Commission is using the Mental Capacity Act in its inspections of hospitals such as Winterbourne View, or even acute hospitals, in order to ensure that people with learning disabilities are being included appropriately in decision-making?

**Dr Margaret Flynn:** I believe that the Care Quality Commission are currently piloting work on interviews with patients with learning disabilities. I have been party to a meeting about the interview schedule, and I have to say I did have some concerns about asking 100 yes/no questions of adults with learning disabilities. We do know that there is a tendency to acquiesce when people are uncertain and maybe have limited educational experience. I have expressed my concern. I do 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 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 that 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. 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 the 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 their inventive and protesting voices, or they may 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 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, primarily, 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 area 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, but 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 GPs. 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. 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 more in the code of practice about that.

**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.” That would really uncover the limited impact of the legislation in services for very vulnerable people.

**Q73 Baroness McIntosh of Hudnall:** Could I just pick up, Dr Heslop, what you said about specialist learning disability nurses? To put it very simply, are there enough of them? We had the impression from one of our earlier witnesses, who is a consultant in that field, that there were not very many. Indeed, I think he told us that he was the only consultant in the field in the country. Given that the people that you met who were in that group appeared to be the best informed and the best at interpreting and implementing the Act, should there be more of them? Are they routinely part of every hospital’s cohort or not?

**Dr Pauline Heslop:** They are not routinely employed in every hospital. The confidential inquiry covered five acute hospitals, and there were learning disability liaison nurses in three of those. In the other two hospitals, there was a lead nurse for learning disabilities who also had other responsibilities to her role—so, for example, she was the lead role for dementia and for safeguarding. That obviously eats into her time. I would strongly advocate that there should be at least one—and 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 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.