

HOUSE OF LORDS

Select Committee on the Mental Capacity Act 2005

Report of Session 2013–14

Mental Capacity Act 2005: post-legislative scrutiny

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Select Committee on the Mental Capacity Act 2005

The Select Committee on the Mental Capacity Act 2005 has been appointed “to consider and report on the Mental Capacity Act 2005”.

Membership

Rt Hon the Lord Hardie (Chairman)
The Lord Alderdice
The Baroness Andrews OBE
The Baroness Barker
The Baroness Browning
The Lord Faulks (until 18 December 2013)
Professor the Baroness Hollins
The Baroness McIntosh of Hudnall
Professor the Lord Patel of Bradford OBE
Rt Hon the Baroness Shephard of Northwold
The Lord Swinfen
The Lord Turnberg

Declarations of interests

See Appendix 1.

A full list of Members’ interests can be found in the Register of Lords’ Interests:

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CONTENTS

	<i>Paragraph</i>	<i>Page</i>
Summary		6
Conclusions and Recommendations		8
Chapter 1: Introduction	1	21
The role of post-legislative scrutiny	6	22
Overall finding	12	23
Keeping the Act under review	21	24
Chapter 2: Background to the Mental Capacity Act	23	25
What did the Act intend to achieve?	23	25
How did the Government set out to achieve it?	27	26
How did the Government intend to measure success?	33	27
Measuring public attitudes	37	28
Chapter 3: The five core principles: Is the Act working as intended?	40	29
Context of the health and social care sector	43	29
Changes in the human rights framework	51	31
Implementation of the Core Principles	54	32
Box 1: The principles of Mental Capacity Act		33
The first principle: presumption of capacity	56	33
Capacity assessments	59	34
Box 2: Assessing Capacity Section 3 of the Act		34
Quality of capacity assessments	66	37
Box 3: The case of Steven Neary		38
Assessing capacity in adults with specific conditions	71	38
What triggers an assessment?	74	39
The second principle: supported decision-making	79	41
Box 4: Jim Blair, learning disability nurse consultant & hospital passports		42
The third principle: unwise decisions	84	43
The fourth principle: best interests	90	44
Box5: Best Interests, section 4		45
The fifth principle: the least restrictive option	102	50
Conclusions and recommendations	103	50
Chapter 4: Addressing poor implementation of the Act	111	52
Oversight of organisations	119	53
Training and oversight of professionals: the role of professional regulators and medical Royal Colleges	128	56
Commissioning	143	59
Access to advice and information on the MCA	154	62
The Codes of Practice	155	62
Box 6: A case study of what works		64
Chapter 5: Advocacy and Advance Planning	163	66
Independent Mental Capacity Advocates	164	66

Lasting Powers of Attorney	179	70
Advance decisions to refuse treatment (ADRTs)	193	75
Chapter 6: The Court of Protection	201	78
Is the Court of Protection appropriate?	202	78
Delays	205	79
Transparency	212	81
A Mental Capacity Tribunal?	220	82
Mediation	224	84
Access to the Court	233	86
Legal Aid	238	87
Chapter 7: Deprivation of Liberty Safeguards	253	91
Background	253	91
Box 7: The Bournemouth gap		91
Overview of findings	256	92
Use of the Deprivation of Liberty Safeguards	261	93
Criticisms of the legislation	271	95
Why are the safeguards not working in practice?	273	96
Failure to apply the principles	273	96
Complexity	275	97
A definition?	279	98
Unhelpful nomenclature	284	99
The effectiveness of the Relevant Person's Representative role	286	99
The effectiveness of the supervisory body role	289	100
Potential new gaps	294	101
The eligibility criteria and a 'new Bournemouth gap'?	298	101
Chapter 8: Criminal Law Provisions	301	103
Box 8: Ill-treatment or neglect		103
Appendix 1: List of Members and Declarations of Interest		106
Appendix 2: List of Witnesses		109
Appendix 3: Call for Evidence		118
Appendix 4: Letter from Norman Lamb MP-6 November 2013		121
Appendix 5: Letter from Norman Lamb MP-28 November 2013		124
Appendix 6: Letter from Norman Lamb MP-9 December 2013		125
Appendix 7: Letter from Lord McNally-10 December 2013		127
Appendix 8: Memorandum from Ministry of Justice 12 February 2014		129
Appendix 9: Report of a special meeting of the Forget-Me-Nots		130
Appendix 10: Note of the Committee visit to the Court of Protection-20 November 2013		135
Appendix 11: Note of the Committee visit to meet adults with learning disabilities-28 November 2013		139
Appendix 12: Glossary of Acronyms		143

NOTE: Evidence is published online at <http://www.parliament.uk/mental-capacity-act-2005/> and available for inspection at the Parliamentary Archives (020 7219 5314)

References in footnotes to the Report are as follows:

Q refers to a question in oral evidence;

Witness names without a question reference refer to written evidence.

In order to protect individuals, some witnesses are referred to by their initials only.

SUMMARY

We were established in May 2013 to conduct post-legislative scrutiny of the Mental Capacity Act 2005. Our task was to answer the question of whether the Act is working as Parliament intended.

The Mental Capacity Act was a visionary piece of legislation for its time, which marked a turning point in the statutory rights of people who may lack capacity—whether for reasons of learning disability, autism spectrum disorders, senile dementia, brain injury or temporary impairment. The Mental Capacity Act placed the individual at the heart of decision-making. Capacity was to be presumed unless proven otherwise. Decision-making was to be supported to enable the individual as far as possible to take their own decisions. Unwise decisions were not to be used as indicators of a lack of capacity—like others, those with impairments were entitled to take risks and to make poor decisions. When a person was found to lack capacity for a specific decision, the ‘best interests’ process ensured that their wishes and feelings were central to the decision being made and, importantly, provided protection from harm to vulnerable adults. The Act signified a step change in the legal rights afforded to those who may lack capacity, with the potential to transform the lives of many. That was the aspiration, and we endorse it.

Our findings suggest that the Act, in the main, continues to be held in high regard. However, its implementation has not met the expectations that it rightly raised. The Act has suffered from a lack of awareness and a lack of understanding. For many who are expected to comply with the Act it appears to be an optional add-on, far from being central to their working lives. The evidence presented to us concerns the health and social care sectors principally. In those sectors the prevailing cultures of paternalism (in health) and risk-aversion (in social care) have prevented the Act from becoming widely known or embedded. The empowering ethos has not been delivered. The rights conferred by the Act have not been widely realised. The duties imposed by the Act are not widely followed.

One reason for the Act’s patchy implementation is that there is no central ownership of the Act. There are many bodies involved in its implementation but no single body has responsibility for it. It is the priority of none. This is in part due to the scope of the Act—it applies very widely and is not restricted to a specific setting or defined group of people. However, the failure to provide a focal point for ownership and oversight has allowed it to be largely unimplemented.

Our principal recommendation to address the failure to embed the Act in every day practice is that responsibility for oversight of its implementation should be given to a single independent body. This body could be free-standing or located within an existing organisation. Its role would be to oversee, monitor and drive forward the implementation of the Act. We provide a ‘job description’ for the independent oversight body below. The independent oversight body would not remove ultimate responsibility for the Act from Ministers, but it would locate in one place ownership of the Act and thereby provide a form of accountability, and a focus for enhanced activity.

Our other key recommendation concerns the Deprivation of Liberty Safeguards. We considered the safeguards separately from the rest of the Act, which is largely how they were perceived by our witnesses. They were inserted into the Mental Capacity Act by the Mental Health Act 2007, designed to fill a gap in the legislative framework identified in the case of *HL v UK* in the European Court of Human Rights. The intention behind the safeguards—to provide protection in law for individuals who were being deprived of their liberty for reasons of their own safety—was understood and supported by our witnesses. But the legislative provisions and their operation in practice are the subject of extensive and wide-ranging criticism. The provisions are poorly drafted, overly complex and bear no relationship to the language and ethos of the Mental Capacity Act. The safeguards are not well understood and are poorly implemented. Evidence suggested that thousands, if not tens of thousands, of individuals are being deprived of their liberty without the protection of the law, and therefore without the safeguards which Parliament intended. Worse still, far from being used to protect individuals and their rights, they are sometimes used to oppress individuals, and to force upon them decisions made by others without reference to the wishes and feelings of the person concerned.

The only appropriate recommendation in the face of such criticism is to start again. We therefore recommend a comprehensive review of the Deprivation of Liberty Safeguards with a view to replacing them with provisions that are compatible in style and ethos to the rest of the Mental Capacity Act.

We make other recommendations about the operation of the Act throughout the report. A full list of our conclusions and recommendations can be found at the beginning of the report.

Independent Oversight Body for the implementation of the Mental Capacity Act—a job description

The independent oversight body will oversee, monitor and drive forward implementation of the Act. It should reflect in its composition the professional fields within which the Act operates, as well as the range of people directly affected by the Act, and their families and carers. This will be essential for its credibility and acceptance. The independent body will not be a regulator or an inspectorate, although it will work closely with regulators who have responsibilities in relation to the Act.

We recommend that the independent oversight body should:

- Have responsibility for oversight, co-ordination and monitoring of implementation of the Act;
- Work closely with relevant regulators and professional bodies to ensure that the Act is given a higher profile in training, standard setting and enforcement;
- Provide support for professionals required to implement the Act;
- Drive improved public awareness of the Act, and introduce robust awareness measures;
- Present a report on its activities to Parliament annually.

CONCLUSIONS AND RECOMMENDATIONS

Implementation of the Core Principles: Is the Act working as intended?

1. We acknowledge the wide-spread support which the Act enjoys among stakeholders. It is described in unusually enthusiastic language. It is disappointing therefore that the implementation of the Act has yet to receive the same acclaim. (paragraph 103)
2. The empowering ethos of the Act has not been widely implemented. Our evidence suggests that capacity is not always assumed when it should be. Capacity assessments are not often carried out; when they are, the quality is often poor. Supported decision-making, and the adjustments required to enable it, are not well embedded. The concept of unwise decision-making faces institutional obstruction due to prevailing cultures of risk-aversion and paternalism. Best interests decision-making is often not undertaken in the way set out in the Act: the wishes, thoughts and feelings of P are not routinely prioritised. Instead, clinical judgments or resource-led decision-making predominate. The least restrictive option is not routinely or adequately considered. This lack of empowerment for those affected by the Act is underlined by the fact that many responsible for its implementation continue to consider it as part of the safeguarding agenda. (paragraph 104)
3. The presumption of capacity, in particular, is widely misunderstood by those involved in care. It is sometimes used to support non-intervention or poor care, leaving vulnerable adults exposed to risk of harm. In some cases this is because professionals struggle to understand how to apply the principle in practice. In other cases, the evidence suggests the principle has been deliberately misappropriated to avoid taking responsibility for a vulnerable adult. (paragraph 105)
4. The rights and responsibilities of the different stakeholders which are properly conferred under the Act are largely unknown. This makes the effective exercise of those rights, and the proper discharge of those responsibilities almost impossible. (paragraph 106)
5. The general lack of awareness of the provisions of the Act has allowed prevailing professional practices to continue unchallenged, and allowed decision-making to be dominated by professionals, without the required input from families and carers about P's wishes and feelings. (paragraph 107)
6. A fundamental change of attitudes among professionals is needed in order to move from protection and paternalism to enablement and empowerment. Professionals need to be aware of their responsibilities under the Act, just as families need to be aware of their rights under it. We consider how this can be achieved in the next chapter. (paragraph 108)
7. **Recommendation 1: In the first instance we recommend that the Government address as a matter of urgency the issue of low awareness among those affected, their families and carers, professionals and the wider public. (paragraph 109)**
8. We reiterate that our findings on the implementation of the core principles concern the operation of the Act principally in health and social care settings. We have very little evidence on the use of the core principles in other sectors. However, given the poor levels of knowledge and understanding in the

sectors on which the Government targeted its implementation programme, we have no reason to believe that the Act is operating well in other areas.(paragraph 110)

9. **Recommendation 2: We recommend the Government consider urgently the need for assessing usage of the core principles across the range of decisions affecting people lacking capacity, including in sectors such as banking and policing. (paragraph 110)**

Addressing poor implementation of the Act

10. Despite the many organisations involved in implementing the Act, it appears that no single body has overall responsibility for it. This may help to explain the patchy implementation of the Act. Without central ownership and co-ordination of implementation, the very positive benefits of the legislation will not be realised. A permanent, proactive, dedicated and independent resource with responsibility for promoting awareness, understanding and good practice across affected sectors is needed to ensure a step change. (paragraph 113)
11. **Recommendation 3: We recommend that overall responsibility for implementation of the Mental Capacity Act be given to a single independent body. This does not remove ultimate accountability for its successful implementation from Ministers, but it would locate within a single independent body the responsibility for oversight, co-ordination and monitoring of implementation activity across sectors, which is currently lacking. This new responsibility could be located within a new or an existing body. The new independent body would make an annual report to Parliament on the progress of its activities. (paragraph 114)**
12. The proposed independent oversight body would not act as a regulator or inspectorate, but it would work closely with such bodies which have those responsibilities in relation to the Mental Capacity Act. The body should act as a support to professionals required to implement the Act. (paragraph 115)
13. The composition of the new independent body should reflect the professional fields within which the Act applies, and it should contain professional expertise. It should also include representation from those directly affected by the Act as well as their families and carers. This is vital to ensure credibility. Other key features of the independent body will be continuity, expertise, accountability and accessibility. (paragraph 116)
14. **Recommendation 4: The Mental Capacity Act Steering Group is a welcome first step in this direction, and we recommend that it be tasked with considering in detail the composition and structure of the independent oversight body, and where this responsibility would best be located. The former Mental Health Act Commission strikes us as an effective, cost-efficient and credible model from which lessons may be learned. (paragraph 117)**

Oversight of organisations

15. It is clear that the CQC has not used its existing powers to best effect to ensure that the requirements of the Mental Capacity Act are met in practice.

We welcome the recognition by the CQC that a new focus on the Act is required in the way it regulates and inspects services. (paragraph 126)

16. **Recommendation 5: We recommend that the standards against which the CQC inspects should explicitly incorporate compliance with the Mental Capacity Act, as a core requirement that must be met by all health and care providers. Meeting the requirements of the empowering ethos of the Act, and especially in terms of actively enabling supported decision-making, must be given equal status with the appropriate use of the deprivation of liberty safeguards, or their replacement provisions (paragraph 127)**

Training and oversight of professionals: the role of professional regulators and medical Royal Colleges

17. The Act needs a higher profile among professionals in order to be properly understood and effectively implemented. The medical Royal Colleges and professional regulators have a responsibility to play their part in promoting best practice through standard setting, training, awareness-raising and enforcement. (paragraph 137)
18. **Recommendation 6: We recommend the Government work with professional regulators and the medical Royal Colleges to ensure that the Act is given a higher profile. This work should emphasise the empowering ethos of the Act, and the best interests process as set out in section 4 of the Act. In future, we would expect the responsibility for this to sit with the independent oversight body. (paragraph 138)**
19. **Recommendation 7: In particular, we recommend that the GMC:**
 - ensure that there is leadership in psychiatry within all medical schools in order to give a higher profile to mental health;
 - place proper emphasis on the Mental Capacity Act in its publication 'Good Medical Practice';
 - enhance training on the Mental Capacity Act in all post-graduate education, especially for GPs. (paragraph 139)
20. **Recommendation 8: The proposed fourth year of training for GPs provides an opportunity to embed and enhance understanding of the Mental Capacity Act with this group of practitioners. We recommend that the Government supports the proposal in light of the vital role which GPs play in providing health care in the community. (paragraph 140)**
21. Consistency in training and oversight of professionals is essential. Whatever body is given responsibility for the implementation of the Act will have a vital role in co-ordinating the response of the medical Royal Colleges and professional regulators to ensure a shared understanding of legal obligations under the Act is used by all. (paragraph 141)
22. We expect that the existence of an independent oversight body with responsibility for implementation of the Act will act as a spur to the medical Royal Colleges and the professional regulators in taking forward work to raise the profile of the Mental Capacity Act and ensure compliance. (paragraph 142)

Commissioning

23. Commissioning has a vital role to play in ensuring that the Act is implemented and complied with in practice. We have noted examples of how commissioners can promote good practice through support and contractual requirements.(paragraph 151)
24. **Recommendation 9: We recommend that the Government, and subsequently the independent oversight body, work with the Association of Directors of Adult Social Services and NHS England to encourage wider use of commissioning as a tool for ensuring compliance. (paragraph 151)**
25. **Recommendation 10: We recommend that the ‘refresh’ of the NHS Mandate in 2014 include requirements explicitly connected to the implementation of the Mental Capacity Act, based on evidence of good practice gathered from Clinical Commissioning Groups. (paragraph 152)**
26. **Recommendation 11: We further recommend that NHS England and ADASS take steps to ensure that the empowering ethos of the Mental Capacity Act is understood and given visibility within commissioning, even where this may appear to conflict with the safeguarding agenda. (paragraph 153)**

Access to Advice and Information

27. A wide range of audiences require information on the Act, ranging from medical practitioners to local authorities, legal professionals, families, carers and people who may lack capacity. Current methods of provision, principally the Codes of Practice, are not meeting the needs of all concerned. (paragraph 159)
28. We do not believe that a standard review of the Code of Practice is adequate to meet the information needs identified. A broader approach to meeting the diverse needs is required, with the possibility of several tailored resources being designed for different audiences. Some of these resources could be provided exclusively online in order to be updated in line with case law. (paragraph 160)
29. **Recommendation 12: We recommend that, in the first instance, the Mental Capacity Act Steering Group give consideration to how the specific information needs of the different groups affected by the Act can best be met. We recommend that the Steering Group take into account the needs of different audiences for different types of information: for example, legal practitioners will be interested in latest developments in case law; a carer may need a brief summary of their responsibilities under the Act; a person lacking capacity may need their rights presented in an accessible format. In future, ensuring the regular review of such information resources would be the responsibility of the independent oversight body. (paragraph 161)**
30. It will be important for consistent information to be provided across professional groups and sectors, including those outside health and social care. The independent oversight body which we recommend should in future co-ordinate between regulators and professional bodies to ensure a common understanding of the Act. (paragraph 162)

Deprivation of Liberty Safeguards

31. Despite the clear intention from Government to close the ‘Bournewood gap’, our evidence suggests that the Deprivation of Liberty Safeguards are frequently not used when they should be, leaving individuals without the safeguards Parliament intended. (paragraph 256)
32. The level and breadth of criticism of the Deprivation of Liberty Safeguards, including from the judiciary, demonstrates that the legislation is not fit for purpose. Better implementation would not be sufficient to address the fundamental problems identified. (paragraph 257)
33. **Recommendation 13: We therefore recommend that the Government undertake a comprehensive review of the DoLS legislation with a view to replacing it with provisions that are compatible in style and ethos with the Mental Capacity Act. The model of widespread consultation that preceded the Mental Capacity Act itself should be followed, with adequate time allowed for effective Parliamentary scrutiny. (paragraph 258)**
34. **Recommendation 14: We further recommend that the independent body with responsibility for oversight and coordination of implementation of the Mental Capacity Act develop a comprehensive implementation action plan to accompany new legislation, in consultation with professionals, individuals, families and unpaid carers. (paragraph 259)**

Use of the Deprivation of Liberty Safeguards

35. We are concerned that there is a very real risk that the Deprivation of Liberty Safeguards are frequently not used when they should be, leaving individuals without the safeguards Parliament intended, and leaving care providers vulnerable to legal challenge. (paragraph 270)

Failure to apply the principles

36. **Recommendation 15: We recommend that replacement legislative provisions make a clear link to the principles of the Mental Capacity Act to ensure consistency with the empowering ethos of the Act as a whole. (paragraph 274)**

Complexity

37. **Recommendation 16: We recommend that replacement legislative provisions and associated forms be drafted in clear and simple terms, to ensure they can be understood and applied effectively by professionals, individuals, families and carers. (paragraph 277)**
38. We note that the Code of Practice to the Mental Health Act 1983 is due for review in 2014. Clarification on the relationship between the Mental Capacity Act and the Mental Health Act is urgently required to assist practitioners. (paragraph 278)

A definition?

39. We agree with the Government and the Official Solicitor that no statutory definition of “deprivation of liberty” is currently required. While the lack of a definition may reduce certainty, the term was intended to echo the wording of Article 5 of the European Convention on Human Rights, and the current statutory provisions are adequate to achieve this. At the same time, action is clearly needed to assist health and social care practitioners in identifying such a deprivation. We address training and awareness raising in chapter 4. (paragraph 283)

Unhelpful nomenclature

40. The term ‘deprivation of liberty’ is unhelpful, but it may not be possible to eliminate its use even with replacement provisions, given that it derives from Article 5 of the European Convention on Human Rights. (paragraph 285)
41. **Recommendation 17: Better understanding of the purpose behind the safeguards is urgently required, and we recommend that achieving this be made a priority by the independent oversight body.** (paragraph 285)

The effectiveness of the Relevant Person’s Representative role

42. In principle the establishment of the role of the Relevant Person’s Representative has been positive. However it does not always provide an effective safeguard for P’s rights when challenging local authorities. (paragraph 288)
43. **Recommendation 18: We recommend that the Government consider how the role of the Relevant Person’s Representative could be strengthened in replacement legislative provisions to provide an effective safeguard.** (paragraph 288)

The effectiveness of the supervisory body role

44. The evidence suggests that supervisory bodies are not consistently providing the safeguard intended, indicated in part by the regional variations in how they discharge their functions. (paragraph 292)
45. **Recommendation 19: We recommend that effective oversight of any future supervisory body function be provided for in the replacement provisions for the Deprivation of Liberty Safeguards.** (paragraph 293)

Potential new gaps

46. Vulnerable adults living in supported accommodation are at risk of being unlawfully deprived of their liberty because they fall outside the scope of the Deprivation of Liberty Safeguards. Although recourse to the Court of Protection is available, evidence of the barriers individuals face in accessing the Court, and of the failure by local authorities to bring cases to Court when necessary, suggests that this is unlikely to provide the safeguards intended. (paragraph 296)

47. **Recommendation 20: We recommend that replacement legislative provisions extend to those accommodated in supported living arrangements. (paragraph 297)**

The eligibility criteria and a 'new Bournewood gap'?

48. **Recommendation 21: We consider that a 'new Bournewood gap' has been inadvertently created by the attempt to prevent overlap with the Mental Health Act 1983. We recommend that replacement legislative provisions close this gap. (paragraph 300)**

Independent Mental Capacity Advocates

49. The role of the IMCAs has been widely praised and much of the evidence calls for their role to be extended. We believe that extending the range of circumstances in which IMCAs are appointed, and involving them earlier in the decision-making process, would be beneficial. (paragraph 175)
50. **Recommendation 22: We recommend that local authorities use their discretionary powers to appoint IMCAs more widely than is currently the case. To support this, we recommend the Government issue guidance to local authorities and health service commissioners about the benefits of wider and earlier use of IMCA services. We believe the costs of greater IMCA involvement should be balanced against the resources required in lengthy disputes or ultimately in litigation. (paragraph 176)**
51. **Recommendation 23: Given the importance of the role of IMCAs in the lives of vulnerable adults we believe that the role requires further professionalisation to ensure consistency of service. This should be achieved through national standards and mandatory training in the Mental Capacity Act and the role of the IMCA within that. We recommend that responsibility for such standards and training be undertaken by the independent oversight body which we recommend in chapter 4, enabling peer support and consistency between IMCA services. (paragraph 177)**
52. **Recommendation 24: We recommend that the Government consider the establishment of a form of self-referral for IMCA services to prevent the damaging delay that occurred in the case of Mr Steven Neary. (paragraph 178)**

Lasting Powers of Attorney

53. As with other aspects of the Mental Capacity Act, low levels of awareness have affected implementation of the provisions relating to Lasting Powers of Attorney. Awareness needs to be raised among the general public of the benefits of Lasting Powers of Attorney in order to encourage greater take-up, especially for Health and Welfare matters. We support the initiatives of the Public Guardian to improve take-up by simplifying the forms and reducing the cost of registration, as well as identifying other barriers to take-up. (paragraph 191)
54. **Recommendation 25: We recommend that the Government, working with the independent oversight body recommended in chapter 4, and the Office of the Public Guardian:**

- **address the poor levels of understanding of LPAs among professional groups, especially in the health and social care sector, paying specific attention to the status of Lasting Powers of Attorney in decision-making;**
- **consider how best to ensure that information concerning registered Lasting Powers of Attorney can be shared between public bodies, and where appropriate with private sector bodies such as banks and utilities;**
- **issue guidance to local authorities that their new responsibilities for provision of information in relation to care contained in the Care Bill should include information on Lasting Powers of Attorney;**
- **consider how attorneys and deputies faced with non-compliance by public bodies or private companies can be supported in the absence of specific sanctions;**
- **review the apparent anomalies in the current arrangements with regard to successive replacement attorneys, and the status in England of Scottish Powers of Attorney. (paragraph 192)**

Advance decisions to refuse treatment (ADRTs)

55. Advance decisions to refuse treatment are an essential means of allowing individuals to determine their care in the event that they lose capacity. As with other aspects of the Act, the general public cannot benefit from this opportunity if they are not made aware of it. Similarly, advance decisions that are not recorded and shared with relevant public bodies are likely to be ineffective. Poor understanding among health and care staff needs to be addressed in order to promote the benefits of advance decisions to patients, as well as to ensure that they are followed when valid and applicable. (paragraph 199)
56. **Recommendation 26: We recommend that the Government, working with the independent oversight body:**
- **urgently address the low level of awareness among the general public of advance decisions to refuse treatment;**
 - **promote better understanding among health care staff of advance decisions, in order to ensure that they are followed when valid and applicable;**
 - **promote early engagement between health care staff and patients about advance decisions to ensure that such decisions can meet the test of being valid and applicable when the need arises;**
 - **promote the inclusion of advance decisions in electronic medical records to meet the need for better recording, storage and communication of such decisions. (paragraph 200)**

The Court of Protection

Delays

57. We note the considerable strain on the processing of applications to the Court of Protection, due to the increased volume of work and significant cuts in staffing. Despite the appointment of authorised officers to handle non-controversial property and financial affairs applications, there continues to be a bottleneck in the process. We are concerned that the means by which this bottleneck is currently eased is from the pool of District Judges. It is questionable whether a system which relies on District Judges deputising for non-judicial staff is cost-effective or proportionate. (paragraph 209)
58. **Recommendation 27: We recommend the Government consider increasing the staff complement of authorised officers, following consultation with the Court of Protection, to achieve a significant reduction in the time taken to deal with non-contentious property and financial affairs cases. (paragraph 210)**
59. **Recommendation 28: We also recommend that the Government consider as a matter of urgency the updating of the Rules of the Court, as recommended by the ad hoc Rules Committee and, as necessary, in light of subsequent changes. (paragraph 211)**

Transparency

60. We believe that the reputation of the Court will improve with greater transparency. We therefore welcome the decision by the President of the Court of Protection to make more judgments available to the public. (paragraph 216)
61. We are persuaded that the Court of Protection has a range of audiences requiring access to information for professional or personal reasons, and that the staff and judiciary of the Court are best placed to determine what that information should be. (paragraph 218)
62. **Recommendation 29: We recommend that the Government consider enabling the Court to address the needs of its audiences either by giving it greater control of the information provided on www.gov.uk or by enabling the Court to have a dedicated website. (paragraph 219)**

Tribunal

63. While we have sympathy with concerns raised regarding access and delay, we believe that the replacement of the Court with a new tribunal system would risk the loss of expertise and potentially increase costs in the system. We therefore conclude that a new tribunal system would not be the best way to address these concerns. (paragraph 223)

Mediation

64. The Office of the Public Guardian appears to be well placed to provide a mediation service in cases of dispute involving holders of Lasting Powers of Attorney or Court appointed deputies. We are concerned, however, that their proposed pilot study will not provide robust data upon which to make a

decision about the feasibility of such a service because of the small sample size and the decision to conduct mediation by telephone. (paragraph 230)

65. Mediation under the Mental Capacity Act should conform to the decision-making framework set out in the Act, and provision must be made to ensure that the views and wishes of P are adequately represented and central to the outcome. We recommend that the evaluation of the mediation pilot by the Office of the Public Guardian includes consideration of the extent to which the principles of the Act were reflected in the process. (paragraph 31)
66. **Recommendation 30: We are persuaded that mediation would be beneficial in many more cases prior to initiating proceedings in the Court of Protection. We recommend that consideration be given to making mediation a pre-requisite for launching proceedings, especially in cases concerning property and financial affairs where the costs fall to P. (paragraph 232)**

Access

67. We are concerned that the responsibility of public authorities to initiate proceedings in cases of dispute is not widely known or adhered to. We also share the concerns of Professor Fennell and Dr Series regarding the ability of the person concerned to challenge decision-making when all others are in agreement. (paragraph 236)
68. **Recommendation 31: We recommend that the Government, and in future the independent oversight body, provide clearer guidance to public authorities regarding which disputes under the Act must be proactively referred to the Court by local authorities. This should include situations in which it is the person who is alleged to lack capacity who disagrees with the proposed course of action. Efforts must be made to disseminate this guidance to families and carers as well as to local authorities. (paragraph 237)**

Legal Aid

69. The Mental Capacity Act concerns some of the most vulnerable individuals in society, whom the law recognises may require support to make decisions. That such individuals will require support to access the legal system is indisputable. (paragraph 248)
70. **Recommendation 32: We note the pressures on legal aid, but we are concerned by the inconsistent provision of non-means tested legal aid for cases concerning a deprivation of liberty, including those where there is a dispute over whether a deprivation is taking place. We cannot see a justification for such inconsistency and we recommend that the gap in protection that it creates be remedied as a matter of urgency. (paragraph 249)**
71. We are concerned by reports that those found to lack litigation capacity are prevented from bringing proceedings due to a lack of legal aid, and note the concerns raised in this regard by the Joint Committee on Human Rights. We are particularly concerned that individuals whom the Court of Protection has asked the Official Solicitor to represent are being refused representation on the grounds of ineligibility for legal aid. (paragraph 250)

72. **Recommendation 33:** We recommend that the Government reconsider the provision of resources to the Official Solicitor, with a view to determining whether some cases merit the same unconditional support as is currently afforded to medical treatment decisions. (paragraph 251)
73. **Recommendation 34:** We further recommend that the Government review the policy underlying the availability of legal aid for those who lack the mental capacity to litigate and therefore cannot represent themselves. For such people, denial of legal aid may result in having no access to Court. No-one who is found to lack the mental capacity to litigate should be denied access to Court solely because they do not have the means to pay for representation. (paragraph 252)

Criminal Law Provisions

74. We welcome the Government's commitment to discuss with the Crown Prosecution Service and the Association of Chief Police Officers the need to ensure appropriate use is made of section 44 of the Mental Capacity Act. We request that specific information on this be provided in the Government response to this Report. (paragraph 308)
75. **Recommendation 35:** We recommend that the Government initiate a review of whether the offence in section 44 of the Act meets the test of legal certainty; and if it does not, to bring forward new legislative provisions. The results of this review should be published within 12 months of publication of our Report. (paragraph 309)

Measuring success

76. While we recognise that the application of the Act is very wide and a complete picture would be hard to achieve, the absence of any monitoring is indefensible, if the benefits of this legislation are to be delivered.(paragraph 35)
77. **Recommendation 36:** We recommend as a matter of urgency that the Government take steps to establish regular and dedicated monitoring of implementation of the Act, and that this should include all the sectors across which the Act applies. (paragraph 35)
78. **Recommendation 37:** We recommend that the independent body with overall responsibility for implementation of the Act, be given responsibility for ensuring such monitoring takes place. (paragraph 36)

Measuring public attitudes

79. **Recommendation 38:** We recommend that the Government introduce a robust method for measuring public and professional attitudes to issues of capacity, in order to be able effectively to measure any change in the prevailing culture. Ideally, benchmarking of this sort would have taken place prior to the implementation of the Act, but there would still be benefits in starting such activity now. This would be a key task for the independent body to be given overall responsibility for the Act. (paragraph 39)

Keeping the Act under review

80. **Recommendation 39: We recommend that, no more than 12 months after publication of this Report, the Liaison Committee seek evidence from the Government on the actions they have taken in response to the two key recommendations made in the summary of this report. (paragraph 22)**

Mental Capacity Act 2005: post-legislative scrutiny

CHAPTER 1: INTRODUCTION

1. The Committee on the Mental Capacity Act 2005 was established on 16 May 2013 “to consider and report on the Mental Capacity Act 2005”,¹ with a deadline of reporting to the House by 28 February 2014. Over the course of our inquiry we held 15 public evidence hearings at which we questioned 61 witnesses. We received a very large number of written submissions from a wide range of organisations and individuals, including those with direct and personal experience of the Mental Capacity Act, which gave us an indication of the high levels of interest in the Act and the issues which it addresses. In total 216 written submissions were received, of which 206 were accepted as evidence.² The combined volume of written and oral evidence, amounting to over 1,800 pages, is published on our website.³ We are grateful to all our witnesses for their contributions.
2. In addition, a delegation of the Committee met adults with learning disabilities, in a consultation facilitated by Mencap Hammersmith & Fulham branch, to hear directly about the impact of the Mental Capacity Act in their day-to-day lives. Two members of the Committee attended a special meeting of the Forget-Me-Nots, a peer support and advocacy group for people with dementia in East Kent, to hear their views of the Act, and of decision-making in their lives.⁴ Finally, the Committee visited the Court of Protection, gaining valuable insights into the work that is carried out both in the Court and the ‘back office’ functions. We are grateful to the President of the Family Division for facilitating access to the Court and to the staff of the Court of Protection for their assistance in the visit; and to Mencap Hammersmith & Fulham branch and to the Forget-Me-Nots and Innovations in Dementia for facilitating these important meetings.
3. Our inquiry has been evidence-led. The issues which we comment on are those which were drawn to our attention most consistently by witnesses across the many submissions we received and the oral evidence we heard. We have not sought to conduct an exhaustive examination of every section and schedule of the Act.
4. As a result of this approach some sectors feature more heavily than others. The majority of evidence we received focused on the implementation of the Act in health and social care settings, with an inevitable focus on health and

¹ HL Deb, 16 May 2013, col 543.

² Committees have discretion to decline to accept submissions which are deemed extreme or unsuitable for any reason. This may include material which is grossly offensive, breaches confidence or makes accusations about individuals. Committees do not accept as evidence material that has already been published elsewhere.

³ The evidence is published in two volumes and can be found at <http://www.parliament.uk/business/committees/committees-a-z/lords-select/mental-capacity-act-2005/publications/>.

⁴ See appendix 9.

wellbeing. There is somewhat less evidence on decision-making concerning property and financial affairs, and on the other sectors across which the Act applies, such as banking or policing. It is difficult therefore to draw any clear conclusions about the Act's implementation outside the health and social care setting, but in light of what we have heard and received, we would caution against assuming that a lack of evidence suggests that the Act is working well in those sectors.

5. Throughout this report any references to the Mental Capacity Act refer exclusively to the provisions of the Act as passed in 2005, prior to the amendment by the Mental Health Act 2007 which inserted into the Mental Capacity Act the Deprivation of Liberty Safeguards. The safeguards are principally dealt with in chapter 7 of this Report; in chapter 4 in relation to the CQC; and in chapter 5 in relation to advocacy.

The role of post-legislative scrutiny

6. The function of post-legislative scrutiny is to consider legislation in practice; it is not the purpose of post-legislative scrutiny to re-open policy debates which were settled at the time of the passage of the Bill. To fulfil our function we have sought through our evidence-gathering to answer the question of whether the Mental Capacity Act 2005 is working as Parliament intended. It follows therefore that we have focused on the implementation of the Act. Where the evidence has identified gaps in implementation we have reported this and made recommendations for improvement.
7. Post-legislative scrutiny is a relatively new activity for the House of Lords. The first House of Lords Select Committee appointed specifically to undertake post-legislative scrutiny was established in May 2012, "to consider the statute law on adoption".⁵ In its Report, published in March 2013, it made the following comments: "where relevant we have commented on the legislation, but more frequently we have made recommendations concerning practice. One conclusion we draw from this is that legislation is only part of the picture ... and there should be more emphasis on practice".⁶
8. We find significant congruence between that conclusion and our own inquiry. We agree with the Minister of State for Care and Support, Norman Lamb MP, who told us, "You can get it absolutely right on paper but it does not necessarily mean that it happens on the ground and changes people's lives".⁷
9. We also note the positive impact an inquiry such as ours can have in shining a light on an area of policy which might otherwise be neglected. When we began our evidence hearings the departmental officials from the Ministry of Justice and Department of Health gave a confident assessment that the Act had been "a success", although it was conceded that it would take "time to embed".⁸ Since then the Government has seen fit to establish the Mental Capacity Act Steering Group whose main purpose, we were told, is "to agree a joint programme of action to continue to implement the Mental Capacity

⁵ HL Deb, 21 May 2012 col 636.

⁶ Select Committee on Adoption Legislation, *Adoption: Post-legislative Scrutiny* (2nd Report, Session 2012-13, HL 127), paragraph 13.

⁷ Q 320.

⁸ Q 1.

Act and the Deprivation of Liberty Safeguards”.⁹ In our final evidence session on 3 December Lord McNally, then Minister of State for Justice, conceded that while getting the Act onto the statute book had been a success, ensuring that it was fully implemented and understood was “work in progress”.¹⁰

10. We welcome the establishment of the Steering Group, and we are pleased that Mr Lamb has undertaken to consult with service users, families and carers about whether or not the Act is being used successfully.¹¹ We also welcome the recognition by Government that work needs to continue on implementing the Act. We hope our report will assist the work of the Steering Group, and have directed recommendations to the Steering Group where appropriate.
11. We also noted the publication in January 2014 of the Care Quality Commission’s report on the implementation of the Deprivation of Liberty Safeguards,¹² which adopted a proactive tone in terms of the steps necessary to improve implementation of the Mental Capacity Act. We welcome this approach.

Overall finding

12. The vast majority of our witnesses considered that the Act was a very significant and progressive piece of legislation, with the potential to transform lives. Its principles remained appropriate and relevant. It provides empowerment for those who may lack capacity; a structure for decision-making for those who do lack capacity; and protection for carers, families and professionals.
13. However, the overwhelming theme of the evidence was that the Act was not well implemented. The principles of the Act, which govern the empowering ethos, are not widely embedded. The processes outlined in the Act—how capacity is to be assessed, how a best interests decision is to be made—are not widely known, and not adequately or consistently followed. In general, the evidence suggested that these problems were greater in health care than in social care settings.
14. Poor implementation appeared to be a function of low awareness combined with poor understanding of the Act: this was a consistent theme identified across professions, families, carers and the wider public. Health and social care professionals continue to struggle with how to apply the core principles in practice. Greater levels of awareness and better understanding will be required to deliver the “quiet revolution in public attitudes and practice” which the Act was expected to usher in.¹³

⁹ Letter from Norman Lamb MP, Minister of State for Care and Support, 6 November 2013. See appendix 4.

¹⁰ Q 312.

¹¹ Letter from Norman Lamb MP, Minister of State for Care and Support, 28 November 2013. See appendix 5.

¹² Care Quality Commission, *Monitoring the use of the Mental Capacity Act Deprivation of Liberty Safeguards in 2012/13*, January 2014:
<http://collateral.vuelio.uk/RemoteStorage/CSCI/Releases/78/20140115%20DoLS.pdf>.

¹³ HC Deb, 18 June 2004, cols 67-70WS.

15. A consistent theme in the evidence was the tension between the empowerment which the Act was designed to deliver, and the tendency of professionals to use the Act for safeguarding purposes. Prevailing professional cultures of risk aversion and paternalism have inhibited the aspiration of empowerment from being realised.
16. The presumption of capacity as set out in the Act—a person must be assumed to have capacity unless it is established that he does not—is widely misunderstood. At times, it is used to justify non-intervention by health or social care services, either erroneously or, in some cases, deliberately.
17. A further theme is the lack of consistent monitoring of implementation of the Act. Limited data are collected, and from those data that are available only limited inferences can be drawn about the operation of the Act. There is insufficient monitoring of how the Act affects Black and Minority Ethnic communities.
18. Ministers are ultimately accountable for the successful implementation of the Act. The present arrangements are unsatisfactory: there are many organisations involved, but none has overall responsibility for implementation. The lack of co-ordination of activities of the various organisations by a single body is reflected in the patchy implementation of the Act. To address this we recommend that a single independent body be given overall responsibility for the implementation of the Act. This independent body could be free-standing or be located within an existing organisation; we consider its key responsibilities in more detail in chapter 4.
19. The most significant exception to the overall finding that the Act was considered to be a good piece of legislation was the evidence on the Deprivation of Liberty Safeguards. Criticism of the safeguards is widespread and, unlike the rest of the Act, the criticism is not confined to implementation. The Deprivation of Liberty Safeguards were considered to be poorly drafted and poorly implemented. Our principal recommendation to address this is to replace the safeguards with new legislative provisions. The scope and content of the new provisions are considered in chapter 7.
20. We set out our findings and, where relevant, recommendations, in more detail in the subsequent chapters.

Keeping the Act under review

21. We consider it important that the matters in this Report are kept under review, despite the fact that the work of this Committee will end on publication of our Report.
22. **We recommend that, no more than 12 months after publication of this Report, the Liaison Committee seek evidence from the Government on the actions they have taken in response to the two key recommendations made in the summary of this report.**

CHAPTER 2: BACKGROUND TO THE MENTAL CAPACITY ACT

What did the Act intend to achieve?

23. The Mental Capacity Act was the culmination of a very long process of consultation which began in 1989, when the Law Commission undertook a study into the law for decision-making on behalf of persons who lack capacity. A report followed in 1995 recommending that there should be a single comprehensive piece of legislation making provisions for people who lack capacity.¹⁴ A Green Paper was published in 1997,¹⁵ followed by a White Paper in 1999,¹⁶ which subsequently formed the basis of the draft Mental Incapacity Bill. The draft Bill was published in June 2003 and referred to a joint committee for pre-legislative scrutiny. The joint committee reported in November of that year.¹⁷
24. The evidence submitted to the pre-legislative scrutiny committee showed that there was “widespread support” for such a Bill,¹⁸ and the Committee endorsed the Government’s proposal for a “comprehensive statutory framework to define mental capacity, help those lacking it to make their own decisions where they can and enable sound decisions to be made for them when they can not”.¹⁹
25. Finally, in June 2004 the Mental Capacity Bill was introduced.²⁰ The Government said the Bill would “empower, protect and support people who lack mental capacity” and that “professionals, families and friends who care for people who lack mental capacity need to understand more fully and more clearly their legal rights and responsibilities”.²¹
26. The Government expected that the Bill would “over time bring about a quiet revolution in public attitudes and practice”.²² There was recognition from the beginning, however, that the success of the Act would depend on its implementation, which would in turn depend on many individuals working across many different settings. The pre-legislative scrutiny committee agreed that “legislation can only go so far. It must be accompanied by changes in attitude which recognise the rights of those lacking capacity and the need to instil respect and good practice in dealing with them”.²³

¹⁴ Law Commission, *Mental Incapacity*, Law Com 231 (1995).

¹⁵ Who decides? Making Decisions on Behalf of Mentally Incapacitated Adults, December 1997, Cm 3808, : <http://webarchive.nationalarchives.gov.uk/+http://www.dca.gov.uk/menincap/meninfr.htm>.

¹⁶ Making Decisions, October 1999, Cm 4465:

<http://webarchive.nationalarchives.gov.uk/+http://www.dca.gov.uk/family/mdecisions/indexfr.htm>.

¹⁷ Joint Committee on the Draft Mental Incapacity Bill, *Draft Mental Incapacity Bill* (1st Report, Session 2002-03, HL 189-I): <http://www.publications.parliament.uk/pa/jt/jtdmi.htm>.

¹⁸ *Ibid.*, page 13.

¹⁹ *Ibid.*, page 5.

²⁰ The change of name from Mental Incapacity Bill to Mental Capacity Bill was a key recommendation of the Joint Committee on the Draft Mental Incapacity Bill; *Ibid.*, recommendation 99.

²¹ HC Deb, 11 October 2004, col 22.

²² HC Deb, 18 June 2004, col 68WS.

²³ Joint Committee on the Draft Mental Incapacity Bill, *op.cit.*, recommendation 3.

How did the Government set out to achieve it?

27. The Government invested “significant effort in implementation of the Act, in recognition of the scale of cultural change and the changes in working practices ... required”.²⁴ The ‘Mental Capacity Implementation Programme,’ delivered jointly by the Ministry of Justice, the Department of Health, the Office of the Public Guardian and the Welsh Assembly Government, featured the publication of a series of booklets aimed at family, friends and unpaid carers, and professionals in health and social care; a DVD depicting real life stories; and a monthly implementation update newsletter distributed to those in social, health care and legal professions.
28. The Department of Health funded an implementation team with a national manager and nine regional managers. Initially planned for three years, the Department subsequently extended the team’s work to five. During this time the Department:
- commissioned a series of training materials and audit tools;
 - funded support for Independent Mental Capacity Advocates (IMCAs);
 - invited local authorities to set up multi-agency Local Implementation Networks;
 - made additional funding available to local authorities and the NHS to support implementation (from 2008 onwards);
 - worked with partner organisations, including the NHS Confederation, Association of Directors of Adult Social Services, the General Medical Council, the British Medical Association and the voluntary sector; and
 - grant-funded over 50 organisations to update policies, develop good practice guidance, design audit tools and carry out research.
29. However, as Paul Gantley, former national implementation manager at the Department of Health, told us, from 2007 there was “a quite different beast to contend with ...the deprivation of liberty safeguards”.²⁵ The implementation programme after 2007 became focused on the implementation of the new safeguards inserted into the Act by the Mental Health Act 2007.
30. The Department of Health implementation programme came to an end in 2011. Mr Gantley suggested that this was “part of a wider decision” taken in the context of austerity cuts, and that there was no considered assessment that the work was complete.²⁶ Some witnesses argued that this support for implementation was withdrawn too soon.²⁷
31. Assessment of the effectiveness of the implementation programme varied among witnesses. The MCA and MCA DoLS Team of Cambridgeshire County Council said that the programme was effective in providing leadership and guidance,²⁸ while Empowerment Matters CIC argued that it focused too much on professionals and not enough on families and the wider

²⁴ Ministry of Justice.

²⁵ Q 186.

²⁶ Q 186.

²⁷ Q 177.

²⁸ MCA and MCA DoLS Team of Cambridgeshire County Council.

public.²⁹ Hampshire County Council and Camden Safeguarding Adults Partnership Board argued that social care professionals were prioritised over other professional groups, including those in health care settings;³⁰ because, as the College of Social Work suggested, it was assumed that medical professionals would understand the Act.³¹

32. Even those who welcomed the programme questioned its sustainability. The Law Society argued that it lacked an effective means of monitoring implementation and ensuring compliance, and that without these, “it is difficult to see how sustainable change can be effected or appraised”.³²

How did the Government intend to measure success?

33. The regulatory impact assessment for the Mental Capacity Act said that the Government’s objective would be “to ensure that the Bill is working as we expect it to, making a real difference in the lives of vulnerable adults”.³³ However, it conceded that “the most important aspects of the Bill are quite difficult to measure”.³⁴ Instead, the Government would want to reassure itself that “the way in which people who lack capacity are helped to take decisions reflects the principles of the Bill, i.e. people are first assumed to have capacity, allowed to take their own decisions as far as possible, and that others act in their best interests”.³⁵ It concluded that:

“since the main and most widespread change we seek is a difference in how decisions are taken and delivering benefits to the wide group of vulnerable people, this is likely to involve qualitative research as well as reviewing feedback, e.g. MPs’ letters and outcomes such as statistics on court cases, complaints, reports in the media”.³⁶

34. This view was echoed in the evidence provided by the departmental officials at the outset of our inquiry.³⁷ However, there was no evidence of how, or indeed whether, the Government sought to assess progress against the criteria identified for success. When we asked the Minister for Care and Support, Norman Lamb MP, how the Government had measured the way in which the principles of the Act were being implemented in practice, he conceded that the Government had “an incomplete picture” but that he was “open to ideas of what more we can do to gain a better understanding”.³⁸ Consequently, it is not clear to us that the Government took any measures to ascertain whether the Act met the criteria set out above.
35. **While we recognise that the application of the Act is very wide and a complete picture would be hard to achieve, the absence of any monitoring is indefensible, if the benefits of this legislation are to be**

²⁹ Empowerment Matters CIC.

³⁰ Camden Safeguarding Adults Partnership Board; Hampshire County Council.

³¹ Q 140.

³² The Law Society.

³³ Department for Constitutional Affairs, Mental Capacity Act Regulatory Impact Assessment. June 2004, p.19.

³⁴ *Ibid.*

³⁵ *Ibid.*

³⁶ *Ibid.*

³⁷ Q 1.

³⁸ Q 314.

delivered. We recommend as a matter of urgency that the Government take steps to establish regular and dedicated monitoring of implementation of the Act, and that this should include all the sectors across which the Act applies.

36. **We recommend that an independent body with overall responsibility for implementation of the Act, be given responsibility for ensuring such monitoring takes place.**

Measuring public attitudes

37. From the introduction of the Bill to its enactment, there was an expectation from Government and others that a change in public attitudes and practice would develop as a result of the Act. Indeed, the pre-legislative scrutiny committee found that such a change would be essential to its successful implementation (see paragraph 26).³⁹ But the plans for measuring such change were extremely vague and we are not convinced, based on the evidence of officials and ministers, that they were ever acted on.
38. It may be less easy to measure changes in attitude and culture than it is to collect more concrete data, but clearly there are ways to measure awareness and attitudes among professionals and the wider public. This is no substitute for monitoring actual implementation of the Act. However, if a change in public attitudes is considered an important outcome of the Act, and arguably the effective implementation of the Act depends on it, measuring any such change may provide an indicator of success.
39. **We recommend that the Government introduce a robust method for measuring public and professional attitudes to issues of capacity, in order to be able effectively to measure any change in the prevailing culture. Ideally, benchmarking of this sort would have taken place prior to the implementation of the Act, but there would still be benefits in starting such activity now. This would be a key task for the independent body to be given overall responsibility for the Act.**

³⁹ Joint Committee on the Draft Mental Incapacity Bill, *Op.Cit.*, recommendation 3.

CHAPTER 3: THE FIVE CORE PRINCIPLES: IS THE ACT WORKING AS INTENDED?

40. We have already set out our overall finding that the Act is widely supported, but that it is not well embedded in practice (see chapter 1, paragraphs 12-13). The Act was described by a wide range of witnesses in glowing terms: “progressive,”⁴⁰ “positive,”⁴¹ “a wonderful piece of legislation”⁴² and “a force for good”.⁴³
41. A case can be made that in terms of establishing the system and structures required by the Act, its implementation has been effective. As Paul Gantley, former Implementation Manager for the Mental Capacity Act at the Department of Health, told us:
- “There was a new Court of Protection, a new Office of the Public Guardian, a new IMCA service from scratch in about 150 or so local authorities, each commissioned on time, a new offence was put into place, a code of practice that had three versions at different times, there were lasting powers of attorney and so on. From a narrow perspective, we were effective and we achieved those targets”.⁴⁴
42. But Mr Gantley also conceded that “that is not the same as saying the Act is fully implemented or understood. That is a different test”.⁴⁵ This accords with the evidence we received. The test that was being applied by witnesses who argued that the Act was widely not complied with, was whether the core principles, which underpin the empowering ethos of the Act, had been widely understood and embedded in practice; in effect, had there been a revolution in public attitudes and practice, as the Government predicted in 2004? We find this to be an appropriate test. This chapter considers in more detail where, how and why implementation is lagging behind the legislation.

Context of the health and social care sector

43. Most of our evidence concerning the implementation of the core principles focused on the health and social care sectors. We set out briefly some context concerning those sectors, which provides the backdrop to our findings.
44. Standards of care, and especially of care for those with learning disabilities, have received renewed public attention following a number of high profile failures, such as those found at Winterbourne View Hospital. Over the course of our inquiry the Government published its response to the Confidential Inquiry into the Premature Deaths of People with Learning Disabilities (CIPOLD)⁴⁶, concerning preventable deaths which had occurred due to a

⁴⁰ Q 26.

⁴¹ Q 74.

⁴² Michael Loftus.

⁴³ Peter Edwards (Director, Peter Edwards Law).

⁴⁴ Q 185.

⁴⁵ Q 185.

⁴⁶ Department of Health, *Government Response to the Confidential Inquiry into premature deaths of people with learning disabilities*, July 2013: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212077/Government_Response_to_the_Confidential_Inquiry_into_Premature_Deaths_of_People_with_Learning_Disabilities_-_full_report.pdf.

failure to provide equality of care to those with learning disabilities. That inquiry followed on from an earlier report *Healthcare for All*, published in 2008, which reported on access to health care for people with learning disabilities.⁴⁷ The report found that although the legislative framework was clear, there was a failure to deliver adequate services resulting in avoidable suffering and deaths.⁴⁸ The report, sometimes known as the Michael review, after its chairman Sir Jonathan Michael, also pointed to ineffective monitoring of compliance with the (then) legislative framework comprised of the Disability Discrimination Act and the Mental Capacity Act.

45. Also during the course of our inquiry, the Government published its final response to the Francis report,⁴⁹ which had identified systemic, organisational and individual failings which had contributed to “the normalisation of cruelty”⁵⁰ in care at the Mid Staffordshire NHS Foundation Trust. The 2012/13 Annual Report by Healthwatch England cited research in which 94% of the public agreed that the NHS and social services could be improved.⁵¹ Furthermore, 1 in 3 of those surveyed said they knew someone who they believed had experienced a serious mistake, abuse or a preventable illness or death in a health or social care service. While these reports do not relate directly to the Mental Capacity Act, they reveal significant current concerns about the context within which the Act is expected to apply.
46. The role of the Care Quality Commission as regulator for health and social care services in England has also been under scrutiny. The quality of its inspection regime was questioned following the revelation that it had failed to respond to the concerns raised by the whistle-blower at Winterbourne View Hospital in 2010.⁵²
47. There have also been structural changes to the commissioning of health and social care services following the Health and Social Care Act 2012, which moved responsibility for commissioning from Primary Care Trusts and Strategic Health Authorities to NHS England and Clinical Commissioning Groups, from April 2013. Clinical Commissioning Groups are required to work with Local Authorities and others to provide and commission health and social care in each area based on a strategic needs assessment. All Clinical Commissioning Groups are required to have a lead for the Mental Capacity Act as a condition of their registration with NHS England.

⁴⁷ *Report of the Independent Inquiry into Access to Healthcare for People with Learning Disabilities*, July 2008 (sometimes known as the Michael Review, after its chair, Sir Jonathan Michael): http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_106126.pdf.

⁴⁸ *Ibid.*, p 53.

⁴⁹ *Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry*, HC 898-I, II & III: <http://www.midstaffspublicinquiry.com/report>. The Government response can be found in: Department of Health, *Hard Truths: the journey to putting patients first*, January 2014, Cm 8777-I & II: <https://www.gov.uk/government/publications/mid-staffordshire-nhs-ft-public-inquiry-government-response>.

⁵⁰ *Patients First and Foremost: The Initial Government Response to the Report of The Mid Staffordshire NHS Foundation Trust Public Inquiry*, March 2013, p. 5, Cm 8576: <https://www.gov.uk/government/publications/government-initial-response-to-the-mid-staffs-report>.

⁵¹ Healthwatch England, *Annual Report 2012/13*, October 2013. Presented to Parliament pursuant to section 45 C (2) of the Health and Social Care Act 2008 as inserted by the Health and Social Care Act 2012: http://www.healthwatch.co.uk/sites/default/files/full-report-2012-13_0.pdf.

⁵² Flynn, M, *South Gloucestershire Safeguarding Adults Board, Winterbourne View Hospital, A Serious Case Review*, August 2012: <http://www.southglos.gov.uk/Pages/Article%20Pages/Community%20Care%20-%20Housing/Older%20and%20disabled%20people/Winterbourne-View-11204.aspx>.

48. Straitened times and straitened resources are in evidence across the health and social care systems, and many of our witnesses touched on this. It is worth noting the impact which this has had on the voluntary sector. A wide range of organisations representing service users and carers have provided advice and guidance on the Mental Capacity Act since before its implementation. As some elements of public services are reduced or discontinued, there is a corresponding surge towards providers of information, advice and advocacy in the voluntary sector. Not surprisingly those organisations are similarly affected by the economic climate and are not always able to meet such demands.
49. We also note the Report by the former House of Lords Select Committee on Public Service and Demographic Change, *Ready for Ageing?*,⁵³ which pointed to a significant shift in the population, and the likely impact on public services, including health and social care. The report identified that England would see a 51% rise in the number of those aged 65 and over, and a 101% rise in those aged 85 and over, between 2010 and 2030.⁵⁴ It forecast that the number of people in England and Wales aged 65 and over with dementia, would increase by over 80% to 1.96 million between 2010 and 2030.⁵⁵
50. The declining confidence in the standards of care, the very recent structural changes in the commissioning and delivery of health and social care, the growing pressure on services from an ageing population, and the impact of austerity on the public and voluntary sectors, form the backdrop to our inquiry.

Changes in the human rights framework

51. In December 2006 the United Nations adopted the final text of the Convention on the Rights of People with Disabilities. The Convention seeks to remove obstacles which prevent disabled people from accessing the rights enshrined in the Universal Declaration of Human Rights 1948, and to deliver dignity, equality and inclusion for disabled people. The United Kingdom ratified the Convention in June 2009.
52. The Convention contains a number of rights relevant to the Act. Most prominent is article 12, the right to equal recognition before the law. Guidance produced by the Equality and Human Rights Commission explains that this “means that disabled people cannot be denied the right to make their own decisions. If they need help to make decisions, then this should be given”.⁵⁶ The United Nations Committee on the Rights of Persons with a Disability issued a consultation on draft guidance on the meaning of Article 12 in September 2013, after this Committee had begun its inquiry. The deadline for submissions to the consultation was January 2014 and we are not yet aware of its outcome.

⁵³ Select Committee on Public Service and Demographic Change, *Ready for Ageing?* (1st Report, Session 2012-13, HL Paper 140): <http://www.parliament.uk/business/committees/committees-a-z/lords-select/public-services-committee/report-ready-for-ageing/>.

⁵⁴ *Ibid.*, p 7.

⁵⁵ *Ibid.*, p58.

⁵⁶ Equality and Human Rights Commission, The United Nations Convention on the Rights of People with Disabilities, Equality and Human Rights Commission Guidance: *What does it mean for you? A guide for disabled people and disabled people's organisations*, Summer 2010: http://www.equalityhumanrights.com/uploaded_files/publications/uncrpdguide.pdf.

53. We have not sought to review the compatibility of the Act with the Convention, although we understand that the Government has commissioned such an assessment, and we await its outcome.⁵⁷ Given the time frame of the UN Committee’s consultation and the Government’s own assessment, it is reasonable to conclude that the position of the Mental Capacity Act in relation to the Convention is not entirely clear at this time. It would not be prudent therefore for this Committee to make specific recommendations concerning the Act’s compatibility or otherwise with the Convention, and any legislative changes that may or may not be necessary. However, we have received evidence of how the use of the Act in practice could be better aligned with the Convention, and we refer to that where relevant. Although the issue of compatibility cannot be resolved at present it will be relevant in future, and we have therefore taken the view that better alignment in practice should be regarded as a reasonable aim.

Implementation of the Core Principles

54. During the passage of the Bill, as during pre-legislative scrutiny, articulation of the principles of the Act was seen as central to the reform of the law. It formed one of the first recommendations of the pre-legislative committee, who said that “such a statement [of principles] inserted as an initial point of reference could give valuable guidance to the Courts, as well as helping non-lawyers to weigh up difficult decisions”.⁵⁸ The Government agreed, saying that the principles were “the fundamental concepts of the Bill,” and committed to including them in the legislation and in the Codes of Practice.⁵⁹
55. Many witnesses concurred on the significance of the five principles, which were described as “the pillars for the framework in defining capacity and best interests”.⁶⁰ North East London NHS Trust said that “the principles are the single best feature of the Act” which had “the potential to revolutionise healthcare”.⁶¹ The British Institute of Human Rights said the principles ensured “capacity decisions are made in a way that respects, protects and fulfils people’s human rights”.⁶² Mark Neary, father of Steven Neary, who was found to be unlawfully detained by London Borough of Hillingdon in 2010 (see Box 3), described the principles of the Act as “transformative when applied correctly and genuinely in P’s best interests”.⁶³ Nonetheless there was a recognition from some witnesses that applying the principles in practice was challenging: “given the wide range of people and circumstances [the principles] are applied to, these can be in practice, very complex judgements”.⁶⁴

⁵⁷ QQ 5 & 333.

⁵⁸ Joint Committee on the Draft Mental Incapacity Bill, *Op. Cit.*, recommendations 4 & 5.

⁵⁹ The Government response to the Scrutiny Committee’s Report on the draft Mental Incapacity Bill, February 2004, pp. 9-10: <http://webarchive.nationalarchives.gov.uk/http://www.dca.gov.uk/pubs/reports/mental-incapacity.htm>.

⁶⁰ MCA and MCA DoLs’ Team of Cambridgeshire County Council.

⁶¹ North East London NHS Trust.

⁶² British Institute of Human Rights.

⁶³ Mark Neary.

⁶⁴ North Yorkshire County Council.

BOX 1**The principles of Mental Capacity Act**

Mental Capacity Act 2005, section 1, clauses 1-6

- (1) The following principles apply for the purposes of this Act.
- (2) A person must be assumed to have capacity unless it is established that he lacks capacity.
- (3) A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.
- (4) A person is not to be treated as unable to make a decision merely because he makes an unwise decision.
- (5) An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.
- (6) Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action

The first principle: presumption of capacity

56. Section 1(2) of the Act embodies the intention to embed in law the principle that everyone has the right to make their own decisions, and that capacity must be assumed until proven otherwise. Evidence to this inquiry suggests that the implementation of this principle is patchy, at best. The principal reasons for this are a tendency among health and social care staff to make assumptions based on impairment; the failure to conduct assessments when necessary; the poor quality of assessments generally, and the failure to take into account the impact of specific conditions on assessment. We also note poor understanding of the principle of presumption of capacity among professionals, and the difficulties experienced in applying the principle in practice. Disconcertingly, there is evidence of the presumption of capacity being used to support non-intervention by service providers.
57. Advocacy Service Cymru told us that in their experience “patients are deemed to lack capacity on ‘assumptions’ of professionals because of a mental illness, deafness, appearance, age”.⁶⁵ This finding was supported by the Mental Health Foundation, whose research into best interests decision-making had concluded that people were being found to lack capacity “for reasons which the Act does not allow, i.e. a blanket assumption based upon diagnosis or an unwise decision”.⁶⁶ Calls to a helpline operated by Sense, a charity for deaf-blind people, had shown that in medical settings especially “there tends to be an immediate assumption of lack of capacity”.⁶⁷ The same finding was reported by legal practitioners: “There seems to be a

⁶⁵ Advocacy Service Cymru.

⁶⁶ Q 50.

⁶⁷ Q 48.

discriminatory practice that when dealing with certain client groups, e.g. the elderly or learning disabled, it is for them to show that they have capacity”.⁶⁸

58. These views were supported by evidence from parent carers: “The assumption seems to be that if a person has learning disabilities, then they don’t have capacity to make their own decisions”.⁶⁹ One mother of a physically disabled daughter related the following incident:

“My daughter does not lack capacity, however, whilst she was in an intensive care unit she needed a surgical procedure. I arrived at the unit to be seen by two consultants who asked me to sign a form stating that she lacked capacity. I refused to sign the form because she does not lack capacity. I was then told that she was ventilated and sedated so agreed to sign the form with the addition of a statement that the lack of capacity was related to this situation only. I then went into the unit to find her wide awake! On checking with the nurse I discovered that my daughter had not been sedated when the surgeon had been in to see her and that he had made no attempt to discuss the procedure with her or gain her consent. This man had simply observed her existing physical disability and assumed lack of capacity which is contrary to the act”.⁷⁰

Capacity assessments

59. If capacity is in doubt section 3 of the Act sets out how it is to be assessed (see Box 2).

BOX 2

Assessing Capacity Section 3 of the Act

Inability to make decisions

- (1) For the purposes of section 2, a person is unable to make a decision for himself if he is unable—
 - (a) to understand the information relevant to the decision, .
 - (b) to retain that information,
 - (c) to use or weigh that information as part of the process of making the decision, or
 - (d) to communicate his decision (whether by talking, using sign language or any other means).
- (2) A person is not to be regarded as unable to understand the information relevant to a decision if he is able to understand an explanation of it given to him in a way that is appropriate to his circumstances (using simple language, visual aids or any other means).
- (3) The fact that a person is able to retain the information relevant to a decision for a short period only does not prevent him from being regarded as able to make the decision.

⁶⁸ Peter Edwards (Director, Peter Edwards Law).

⁶⁹ John Stockley.

⁷⁰ PD.

- (4) The information relevant to a decision includes information about the reasonably foreseeable consequences of—
- (a) deciding one way or another, or
 - (b) failing to make the decision.

60. Witnesses reported that “in the majority of cases the process of conducting a formal capacity assessment is not completed and not formally recorded”.⁷¹ Furthermore, Toby Williamson, from the Mental Health Foundation, told us that staff appeared to struggle with how to apply the principle of assumption of capacity in practice, and that this could lead to a failure to conduct an assessment:

“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”.⁷²

61. Kirsty Keywood, senior lecturer at Manchester University, referred to the “unanticipated consequences”⁷³ of the empowering ethos of the Act from the perspective of adult safeguarding. She gave examples where vulnerable adults had been left at risk of harm, in some cases leading to their deaths, after having disengaged from services, and where that decision to disengage had not been sufficiently examined by social workers to understand whether the person making it had capacity to do so. When professionals involved in such cases were questioned, their response was that “Well, there is a statutory presumption of capacity”.⁷⁴ Ms Keywood concluded that “there is something about the presumption of capacity as it is currently worded in the Mental Capacity Act that has obscured the thinking of a number of people working at the grass roots”.⁷⁵ Such difficulties in understanding how to apply a statutory duty in practice are not unique to the Mental Capacity Act. The Independent Inquiry into Access to Healthcare for People with Learning Disabilities found that, in relation to the Disability Discrimination Act 2005, health service staff “commonly fail to understand that a right to equal treatment does not mean treatment should be the same”.⁷⁶
62. There appeared to be other reasons for failing to conduct an assessment: Michael du Feu, a Best Interests Assessor, described a “strong reluctance” by some nurses and social workers to undertake an assessment due to a fear that their decision “might be tested by the legal profession in a court of

⁷¹ Advocacy Support Cymru.

⁷² Q 47.

⁷³ Q 26.

⁷⁴ Q 26.

⁷⁵ Q 26.

⁷⁶ *Report of the Independent Inquiry into Access to Healthcare for People with Learning Disabilities*, Op. Cit. July 2008.

law”.⁷⁷ We also received evidence from a GP, Dr Andrew D. Hardie, who argued that capacity assessments as set out by the Act required a legal rather than medical decision, which was “disruptive to medical assessment” and “liable to cause confusion”.⁷⁸

63. We were told of a worrying tendency among local authorities to use the presumption of capacity to avoid taking responsibility for a vulnerable person. Nicola Mackintosh, representing the Law Society, told us that she had seen “lots of cases where a person has been neglecting themselves, and the local authority or the relevant health agency has used the presumption of capacity to allow that to continue”.⁷⁹ This was echoed by the submission from Irwin Mitchell LLP, who suggested that the assumption of capacity was on occasion deliberately used by local authorities “as an excuse to do nothing on the basis of someone being a conscientious refuser of services, on the basis that P is expressing a view and ‘they must be assumed to have capacity’”.⁸⁰ The Law Society referred to the principles of the Act being “applied perversely”, using the presumption of capacity to avoid assessing capacity, “with the implications for associated support and resources”.⁸¹ The British Association of Brain Injury Case Managers put it more starkly: “assessment of capacity is used as an economic tool to justify lack of provision, leaving the disabled person unprotected and those trying to protect them with no means to provide services”.⁸²
64. Such points were echoed in the submissions from family carers who expressed frustration at the misappropriation of the assumption of capacity by health and social care staff to justify poor care. Two separate witnesses who were relatives of adults with learning disabilities reported a failure by care staff to conduct capacity assessments when those adults continued to make unwise choices which risked serious health consequences, including type-2 diabetes.⁸³ One of them referred to the Act as having “a paralysing effect on medical and social care professionals, preventing them from giving the best possible care”.⁸⁴ The Down’s Syndrome Association also reported concerns expressed by families regarding “the simplistic manner in which choice is interpreted by support staff leading to concerns over health and welfare”.⁸⁵
65. Conversely, there was also evidence that a lack of capacity was sometimes assumed in order to justify a decision made by the local authority, which was often resource-led. Nicola Mackintosh told us that she had handled “many, many cases” where “clients have been deemed to lack capacity because the outcome is going to be that the state spends less on them”.⁸⁶

⁷⁷ Michael du Feu.

⁷⁸ Dr Andrew D Hardie.

⁷⁹ Q 27.

⁸⁰ Irwin Mitchell LLP.

⁸¹ The Law Society.

⁸² British Association of Brain Injury Case Managers.

⁸³ DGP; Elizabeth Verdonkschot.

⁸⁴ DGP.

⁸⁵ Down’s Syndrome Association.

⁸⁶ Q 27.

Quality of capacity assessments

66. The quality of capacity assessments was also criticised. Serjeants’ Inn Chambers told us: “A recurring feature of cases we see is low-quality capacity assessments, requiring the capacity assessment to be carried out afresh”.⁸⁷ A group of barristers and solicitors who jointly submitted evidence reported their shared experience that health professionals had a “much weaker knowledge and awareness” of the Act, which led to their capacity assessments being “less thorough and less compliant with the MCA and the Code of Practice, including on basic issues such as the need for an assessment of capacity to be decision-specific”.⁸⁸
67. The British Association of Social Workers conceded that some social workers did not feel equipped to undertake capacity assessments, and that a lack of confidence was to be found more widely among professionals working in hospitals and care homes. As a result there was a tendency to involve specialist services, such as mental health social workers, to carry out the assessments.⁸⁹
68. The carers for HL, whose case in the European Court had led to the introduction of the Deprivation of Liberty Safeguards (see Box 7: The Bournemouth Gap), told us that: “on many occasions [assessments] are not carried out by the best person to understand the decision that needs to be made, [and] not in a setting that suits the person and with insufficient relevant information to allow the person a reasonable chance to make an informed decision”.⁹⁰ This was the experience of Mr Mark Neary, father to Steven Neary who was found to have been unlawfully detained by the London Borough of Hillingdon in 2010 (see Box 3: The case of Steven Neary).⁹¹

“There is a huge pressure on P in these assessments; they are having to demonstrate many things that a non learning disabled person would never have to be assessed on. The Act requires P to be supported through the assessment but if the assessor is meeting P for the first time, they won’t have the knowledge to provide adequate support. At the three assessments Steven had whilst he was detained, neither myself nor his regular support workers were allowed to be present (in case we led Steven, or prejudiced the outcome). This puts P at a considerable disadvantage and from the outset, shows that a supportive process has turned into an adversarial one”.⁹²

⁸⁷ Serjeants’ Inn Chambers.

⁸⁸ Victoria Butler-Cole, Neil Allen, Andrew Bowmer, Julie Cornes, Charlotte Haworth Hird, Laura Hobey-Hamsher, Laura Jolley, John McKendrick, Alex Ruck Keene, Polly Sweeney, Rachel Turner and Paula Scully.

⁸⁹ Q 140.

⁹⁰ Mr and Mrs E.

⁹¹ See *London Borough of Hillingdon v Neary & Anor* [2011] EWHC 1377 (COP).

⁹² Mark Neary.

BOX 3**The case of Steven Neary**

Steven Neary, a young man in his early 20s, has autism and a severe learning disability. He lives at home with his father, with high levels of support funded by London Borough of Hillingdon Council. In December 2009 his father reported to Hillingdon that he was having difficulties coping, and asked to bring forward a scheduled visit to respite care. The council arranged for Steven to stay in a residential support unit. However, staff found Steven's behaviour very challenging and were concerned about his return home. His father wanted him to stay at the unit for a couple of days but agreed to an extension of a couple of weeks in the expectation that Steven would then return home. In fact, the council had already decided that Steven should not be allowed to return home and kept him at the facility for nearly a year, including a period when he was subject to the Deprivation of Liberty Safeguards. During this time plans were made to send Steven to live permanently at a facility in Wales. The Court of Protection held that Steven had been unlawfully detained and ordered that he must return home to live with his father.

69. The group of solicitors and barristers who jointly submitted evidence found that “the best capacity assessments are by people who know P, and who have experience and training in communicating with people with disabilities, and who see their task as assisting P to make a decision, not testing P’s knowledge”.⁹³ Mr Neary concurred: “the assessor needs a solid understanding of how P communicates and that takes time and commitment that isn’t often available. Certainly, in my experience, the time and commitment doing the assessment nowhere near matches the seriousness of the issues at stake for P”.⁹⁴
70. Many of the criticisms raised about the way in which capacity is assessed appear to result from assessments being carried out by professionals who are not closely involved with the care of the person affected (‘P’). This professionalisation of capacity assessments, conducted by those with no established link to the person concerned, has led to some requirements of the Act—such as the need to support P’s communication, or the condition that assessments are time and decision-specific—being more difficult to fulfil in practice.

Assessing capacity in adults with specific conditions

71. Particular concern was expressed regarding the assessment of capacity in adults with specific conditions such as Down’s syndrome, autism and brain injury. The Down’s Syndrome Association questioned whether social workers had the ability to assess correctly the capacity of people with Down’s syndrome, given that “young people with Down’s syndrome often have quite good language skills and so they come across as being more able than they

⁹³ Victoria Butler-Cole, Neil Allen, Andrew Bowmer, Julie Cornes, Charlotte Haworth Hird, Laura Hobe-Hamsher, Laura Jolley, John McKendrick, Alex Ruck Keene, Polly Sweeney, Rachel Turner and Paula Scully.

⁹⁴ Mark Neary.

actually are because they have learnt lots of different social cues to use”.⁹⁵ The National Autistic Society pointed out that assessments were carried out very quickly, and that environmental factors (“the language the person uses or even the colour jumper someone is wearing”)⁹⁶ could have an impact on the assessment; they called for “better understanding of autism”⁹⁷ on the part of the assessors.

72. We received a number of submissions from those working with individuals who had experienced a brain injury, expressing concern about whether those without experience in this field were able correctly to assess capacity.⁹⁸ The British Association of Brain Injury Case Managers summarised the dilemma thus:

“Clients who have a good residual intellect, who present plausibly and articulate their thoughts well are very likely to be considered to have capacity to manage their own affairs, even despite a lengthy history of impulsivity, lack of social judgement, tangential thought processes, problems with attention and a lack of insight into how their cognitive deficits affect their decision making. Yet this is a client group who can still be extremely vulnerable to malign influence and coercion, particularly if they are in possession of a lump sum of money”.⁹⁹

73. Across the submissions concerning brain injury two factors appeared to collide: the difficulty for a non-specialist of assessing the nature of the impairment in a structured interview, and the application of the third principle—the right to make unwise decisions—by social workers, who sometimes interpreted as lifestyle choices what others with expertise in brain injury considered the actions of a vulnerable person suffering from a debilitating injury. One example concerned a local authority who had “found that a very vulnerable client who had sustained 2 brain injuries and was heavily influenced by her boyfriend, had capacity and was simply making a ‘lifestyle choice’ to partake in street prostitution to fund both their drug habits”.¹⁰⁰

What triggers an assessment?

74. In general there appeared to be little clarity about when an assessment should be triggered. Professor Jones suggested this should be remedied within the Act or at least the Code of Practice, which currently refers to complex decisions needing a formal capacity assessment:

“That is not sufficient. Many simple, straightforward decisions relating to a mentally incapacitated person can be extremely important for them. They can be crucial. ‘Who do I live with?’. That is not necessarily a complex issue, but clearly it should be preceded by a formal capacity assessment and a formal best-interests judgment”.¹⁰¹

⁹⁵ Q 84.

⁹⁶ Q 84.

⁹⁷ Q 84.

⁹⁸ British Association of Brain Injury Case Managers; Brain Injury Rehabilitation Trust; Head First.

⁹⁹ British Association of Brain Injury Case Managers.

¹⁰⁰ *Ibid.*

¹⁰¹ Q 27.

75. Several witnesses expressed concern that in medical settings it appeared that an assessment was triggered in most cases only when treatment was refused. Nurses and other staff working with adults with learning disabilities interviewed by Dr Julie McVey admitted that “if a service user implied consent by not resisting care, treatment or interventions then the MCA was not used”.¹⁰² Beverley Dawkins of Mencap and Hannah Barnett of the National Autistic Society, expressed concern about this since it ran the risk of allowing a vulnerable adult to undergo treatment without any of the relevant safeguards provided by a best interests test, as long as they were acquiescent.¹⁰³
76. The written evidence provided by the College of Emergency Medicine seemed to underline this point with a case study of a 45 year-old intoxicated man who had sustained a head injury. According to the case study the man “was not orientated in time or place. He was not able to focus his attention on the interview for more than a couple of minutes”.¹⁰⁴ Despite this it was only after the man “became aggressive to staff and threatened to leave”¹⁰⁵ that an assessment of capacity was undertaken. The oral evidence we received from the College of Emergency Medicine appeared to reinforce the impression given by the case study.¹⁰⁶
77. Conversely, a failure adequately to question a refusal of treatment was also cited as operating against P’s best interests. Dr Pauline Heslop, principal investigator of the Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD) gave examples of when the failure to assess capacity following such a refusal had led to delays to treatment that was necessary and urgent, and resulted in deaths which could have been prevented by a timely assessment and a best interests process. She concluded that “the presumption of capacity is a good starting point, but should be questioned more than it is”.¹⁰⁷ She added that “a person’s over-riding fear of medical intervention is likely to mean that they are unable to weigh up the advantages and disadvantages of investigation and treatment, and a test of capacity should be undertaken in this respect”.¹⁰⁸
78. The British Association of Social Workers told us that in social care settings an assessment of capacity was more usually triggered by a “perception of risk” amongst families or professionals.¹⁰⁹ There was recognition from many witnesses that the instincts of social workers tended to emphasise the need to protect vulnerable adults rather than to enable their decision-making, if necessary by supporting what appeared to be an unwise decision.¹¹⁰ We consider this attitudinal barrier to implementation in more detail below.

¹⁰² Dr Julie McVey (Liverpool University).

¹⁰³ Q 84.

¹⁰⁴ College of Emergency Medicine.

¹⁰⁵ *Ibid.*

¹⁰⁶ Q 163.

¹⁰⁷ Dr Pauline Heslop (CIPOLD).

¹⁰⁸ *Ibid.*

¹⁰⁹ Q 145.

¹¹⁰ Alzheimer’s Society; The College of Social Work; Lancashire County Council DoLS Team; Doncaster Safeguarding Adults Partnership Board; Dorset Advocacy; Peter Edwards (Director, Peter Edwards Law).

The second principle: supported decision-making

79. Section 1(3) of the Act specifies that “a person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success”. The second principle is generally referred to as supported decision-making, and is intended to enable P as much as necessary to be able to make a decision. Our evidence suggests that this is rare in practice. Irwin Mitchell LLP reported that “there is less focus on supporting people with making decisions than assessing whether they can make those decisions or not.”¹¹¹ The Challenging Behaviour Foundation submitted that “those affected by the Act are not being enabled or supported to make decisions for themselves or in their best interests”.¹¹² Instead, we were told, “there is still a tendency to understand the Act as a framework for making decisions for or on behalf of a person rather than encouraging and maximising their participation in the decision making”.¹¹³ The Law Society concluded that “the focus continues to be on protection rather than enablement, and on best interest decision making as opposed to supported decision-making by the impaired person”.¹¹⁴ This was borne out by the Alzheimer’s Society, who reported calls to its helpline about “individuals being deemed to lack capacity to make a decision, rather than being supported to make their own decisions as intended by the legislation”.¹¹⁵
80. The Nuffield Council on Bioethics pointed out that, particularly in cases of dementia, decision-making capacity varied depending on time of day or other circumstances. It advocated a form of supported decision-making which relied on making decisions jointly “with trusted family members”.¹¹⁶
81. The Sussex Partnership NHS Foundation Trust suggested that the requirement for supported decision-making “placed a significant burden on staff” and that “work pressures at times override ethical and legal principles because of a lack of understanding”.¹¹⁷ Cambridgeshire County Council called for “more emphasis [to] be given to the second principle” but it conceded that this raised issues of resources, both in terms of time, and also staff training.¹¹⁸ The impact of reduced resources on supported decision-making was addressed more widely by Mind:

“To assess, engage and empower a person who may lack capacity can be resource intensive. It may require help from speech therapists or occupational therapists or for more time to be devoted to that person by the care staff or clinical team supporting them. There is a risk that in a time of austerity when resources are scarce there will be a temptation to cut corners and to fail to properly give effect to the requirements of the Act”.¹¹⁹

¹¹¹ Irwin Mitchell LLP.

¹¹² Challenging Behaviour Foundation.

¹¹³ Bristol Mind IMCA Service.

¹¹⁴ The Law Society.

¹¹⁵ Alzheimer’s Society.

¹¹⁶ Nuffield Council on Bioethics.

¹¹⁷ Sussex Partnership NHS Foundation Trust.

¹¹⁸ MCA and MCA DoLs’ Team of Cambridgeshire County Council.

¹¹⁹ Mind.

82. The Law Society argued that lack of education, training, time and resources were barriers to the greater use of supported decision-making at present. We did hear examples of good practice however, such as the use of learning disability nurses in acute hospitals, whose presence tended to lead to better implementation of the Act, principally through making small adjustments which enable P to be as involved as possible in decisions relating to his or her care (see Box 4). Such practice underlines the point made by Sir Jonathan Michael that reasonable adjustments, as required by the Disability Discrimination Act 2005, “to make services equally accessible to people with learning disabilities, are not particularly difficult to make”.¹²⁰ We were also very impressed by the endeavours of one particular family, whom a delegation of the Committee met, to support their adult son with learning disabilities to play an active role in the decisions affecting his life. Apart from choosing his daily activities, he had also been supported to vote in two general elections and two London Mayoral elections. His parents had helped to prepare him for each decision by making scrapbooks of the candidates, providing details of their policies and what they stood for. They had provided this information clearly and in small amounts. Each time, the process had taken three months.¹²¹

BOX 4

Jim Blair, learning disability nurse consultant & hospital passports

The Royal College of Nursing told us that where learning disability nurses were practising there was an increased likelihood of the Act being followed. An example of this was the work of consultant learning disability nurse Jim Blair, of St George’s Hospital in London, who, according to the Royal College of Nursing “raises awareness of the patient’s needs to all health professionals involved in care, throughout the care journey of the patient”.¹²²

In articles for *Nursing Management* and *Emergency Nurse*, Jim Blair explained the adjustments that had been implemented at St George’s to improve outcomes for adults with learning disabilities: the first and last appointments of the day were always offered so that people who found it traumatic to wait did not have to do so; double appointments were offered to permit a fuller assessment of needs, so enabling more effective treatment; families of patients with learning disabilities were not restricted to fixed visiting times, allowing them to be on hand to provide support and advocacy to their relative.¹²³ The triage process in the emergency department was slowed down and information provided gradually and in a quiet place to allow patients time to absorb what was happening and to become engaged in their care. The additional time also allowed nurses to assess capacity effectively and to avoid assumptions based on diagnostic conditions.¹²⁴

¹²⁰ *Report of the Independent Inquiry into Access to Healthcare for People with Learning Disabilities*, Op. Cit. July 2008.

¹²¹ Note of the Committee Visit to meet adults with learning disabilities. See appendix 11.

¹²² Royal College of Nursing.

¹²³ Blair, J. (2011) Care adjustments for people with learning disabilities in hospitals, *Nursing Management*, Volume 18, Number 8, December 2011.

¹²⁴ Blair, J. (2012) Caring for people who have intellectual disabilities, *Emergency Nurse*, Volume 20, Number 6, October 2012.

A key part of the adjustments to enable better care was the adoption by St George's of a hospital passport. The passport is completed by the individual and their family and carers, and it provides information on likes and dislikes and how the person communicates, as well as medical information such as allergies. The passport is held by the individual who brings it to hospital for any appointment or emergency admission. Jim Blair explained in *Nursing Management* that "Hospital passports ensure that people with learning disabilities are more involved in their care, and that this care is provided in a more personalised and dignified manner".¹²⁵

83. A number of witnesses emphasised the importance of focusing more on supported decision-making in order to enhance compliance with the United Nations Convention on the Rights of People with Disabilities (see paragraphs 51–53 above). The Mental Disability Advocacy Center (MDAC) argued that as an example of a "substituted decision-making regime," the Act is *prima facie* incompatible with the Convention, but the Act "could be applied in such a way as to reduce the extent of non-compliance".¹²⁶ They suggested placing considerably greater emphasis on supported decision-making, to the point that decision-making based on objective best interests rather than the views of P becomes a last resort, limited to those individuals who cannot communicate their wishes and feelings at all. The Law Society concurred with MDAC that "a greater emphasis on supported as opposed to substitute decision making is needed in order to move towards greater compliance" with the Convention.¹²⁷

The third principle: unwise decisions

84. The right to make an unwise decision, enshrined in section 1(4), underpins the empowering ethos of the Act: "A person is not to be treated as unable to make a decision merely because he makes an unwise decision." Across the evidence, the balance between empowerment and protection emerged as the key challenge to the implementation of the empowering ethos of the Act, and this seems most clear in relation to unwise decision-making. The right to make an unwise decision runs counter to the prevailing cultures in health and social care, which present barriers to implementation.
85. In social work, our evidence suggested, the prevailing culture was towards protection, for which the term 'safeguarding' was often used as a short-hand; others preferred to use the term 'risk-aversion'. The Law Society argued that those without capacity were denied "the dignity to make the choices and take the risks that others can".¹²⁸
86. Dr Ruth Allen, representing the College of Social Work, conceded that "the MCA is not yet fully understood across any profession as an enabling piece of legislation ... it is often seen as bolstering the desire to protect and, in some ways, control people's choice making".¹²⁹

¹²⁵ Blair, J. (2011) Care adjustments for people with learning disabilities in hospitals, *op.cit.*, December 2011.

¹²⁶ Mental Disability Advocacy Center.

¹²⁷ The Law Society.

¹²⁸ *Ibid.*

¹²⁹ Q 139.

87. Others argued that the protection of vulnerable adults was a legitimate consideration: “most practitioners would feel more comfortable defending a decision to protect rather than being accused of being neglectful”.¹³⁰ Mr Robert Nisbet of the British Association of Social Workers said that social workers veered “towards overprotection and safeguarding”, giving an example of an adult with learning disabilities who might make the decision to remain in a physically abusive relationship, and expressed the difficulty a social worker would face in response:
- “it is very difficult to stand up and say, ‘We have assessed this person. We may disagree with what they are doing, but it is their right, as it is my right, to make mistakes in their life and to make unwise decisions.’ I have not seen many people able to do that. Organisations do not permit it, because they are very fearful of scrutiny and the media is very, very powerful, as we have seen over many years”.¹³¹
88. Similar pressures were highlighted by Lancashire County Council: “enabling someone to take risks is scary, and workers can be under tremendous pressure from families and within their own agencies—what if something goes wrong? Whose name will be headlined? The MCA has not made us any less risk averse”.¹³² The role of the media in promoting a culture of risk-aversion was also mentioned by Camden Safeguarding Adults Partnership Board and Cambridge House Advocacy Service.¹³³
89. We were told that in health care “the paternalistic, medical model of care is still dominant”.¹³⁴ The British Psychological Society agreed that “there is still a tendency to act in a paternalistic/authoritarian fashion and make decisions based on the staff’s perception”.¹³⁵ Gloucestershire MCA Governance Group found that a “protection imperative” often existed, especially in hospital settings,¹³⁶ while Kent and Medway MCA Local Implementation Network suggested that many clinicians still find it difficult to “let go of their paternalistic ways”.¹³⁷ A study of health care staff conducted by Dr Julie McVey found a paternalistic model of care where best interests decisions were favoured over someone being found to have capacity and making an unwise decision.¹³⁸ This was also demonstrated by the evidence presented in paragraphs 75–76, where capacity assessments were seen to be triggered when a course of treatment was refused. Paternalism in medical settings is discussed in more detail in the following section.

The fourth principle: best interests

90. As with the other principles, the best interests principle is widely praised but its implementation is problematic. The British Institute of Learning Disabilities told us that “The centrality of the person’s wishes, beliefs, values

¹³⁰ St Mary’s House.

¹³¹ Q 143.

¹³² Lancashire County Council DoLS Team.

¹³³ Camden Safeguarding Adults Partnership Board; Cambridge House Advocacy Service.

¹³⁴ Kent and Medway MCA Local Implementation Network.

¹³⁵ British Psychological Society.

¹³⁶ Gloucestershire MCA Governance Group.

¹³⁷ Kent and Medway MCA Local Implementation Network.

¹³⁸ Dr Julie McVey (University of Liverpool).

and history within a best interest view is very good. However, all too often ‘best interests’ is interpreted in a medical/paternalistic sense which is wholly at odds with that set out in the Act”.¹³⁹ Dr Claud Regnard put it more strongly: “the term ‘best interests’ is probably the most abused and misunderstood phrase in health and social care. It has too often been the vehicle for poor decision-making as described in many of the cases in Mencap’s Death by Indifference reports”.¹⁴⁰

91. The best interests principle in section 1(5) requires that “An Act done, or a decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.” The provisions for determining best interests are set out in detail in Section 4 of the Act (see Box 5: Best Interests, section 4). It appears that in many cases these provisions, especially those concerning the wishes and beliefs of P, and consultation with family and carers, are not well known or used.

BOX 5

Best Interests, section 4

- (1) In determining for the purposes of this Act what is in a person’s best interests, the person making the determination must not make it merely on the basis of—
 - (a) the person’s age or appearance, or
 - (b) a condition of his, or an aspect of his behaviour, which might lead others to make unjustified assumptions about what might be in his best interests.
- (2) The person making the determination must consider all the relevant circumstances and, in particular, take the following steps.
- (3) He must consider—
 - (a) whether it is likely that the person will at some time have capacity in relation to the matter in question, and
 - (b) if it appears likely that he will, when that is likely to be.
- (4) He must, so far as reasonably practicable, permit and encourage the person to participate, or to improve his ability to participate, as fully as possible in any act done for him and any decision affecting him.
- (5) Where the determination relates to life-sustaining treatment he must not, in considering whether the treatment is in the best interests of the person concerned, be motivated by a desire to bring about his death.
- (6) He must consider, so far as is reasonably ascertainable—
 - (a) the person’s past and present wishes and feelings (and, in particular, any relevant written statement made by him when he had capacity),
 - (b) the beliefs and values that would be likely to influence his decision if he had capacity, and

¹³⁹ British Institute of Learning Disabilities.

¹⁴⁰ Dr Claud Regnard FRCP (Consultant in Palliative Care Medicine, St Oswald’s Hospice).

- (c) the other factors that he would be likely to consider if he were able to do so.
- (7) He must take into account, if it is practicable and appropriate to consult them, the views of—
 - (a) anyone named by the person as someone to be consulted on the matter in question or on matters of that kind,
 - (b) anyone engaged in caring for the person or interested in his welfare,
 - (c) any donee of a lasting power of attorney granted by the person, and
 - (d) any deputy appointed for the person by the court, as to what would be in the person’s best interests and, in particular, as to the matters mentioned in subsection (6).
- (8) The duties imposed by subsections (1) to (7) also apply in relation to the exercise of any powers which—
 - (a) are exercisable under a lasting power of attorney, or
 - (b) are exercisable by a person under this Act where he reasonably believes that another person lacks capacity.
- (9) In the case of an act done, or a decision made, by a person other than the court, there is sufficient compliance with this section if (having complied with the requirements of subsections (1) to (7)) he reasonably believes that what he does or decides is in the best interests of the person concerned.
- (10) “Life-sustaining treatment” means treatment which in the view of a person providing health care for the person concerned is necessary to sustain life.
- (11) “Relevant circumstances” are those—
 - (a) of which the person making the determination is aware, and
 - (b) which it would be reasonable to regard as relevant.

92. We heard evidence that, especially in medical settings, the concept of best interests as defined by the Act was not well understood, in part because it was at odds with the concept of best interests as it is used in a medical or clinical sense. Headway, a charity for brain injury patients, reported feedback from one of their members whose sister was in a minimally conscious state following a catastrophic brain injury:

“Staff defined a ‘best interests’ decision as a ‘clinical decision’—and just saw it as a matter of clinical judgment. From the moment of my sister’s accident it was as if she belonged to them, they were not interested in what we knew about her and her wishes. I can understand this in the immediate emergency but this went on for months and months, it was a constant battle”.¹⁴¹

¹⁴¹ Headway.

93. Moira Fraser of the Carers Trust reported that families had the impression that “professionals pick and choose when to involve them”.¹⁴² Furthermore, families who disagreed with the decision being made found they were excluded on the grounds that “they are not acting in the best interests of the person whom they care for”.¹⁴³ Mencap reported that families of adults with learning disabilities were not being consulted by medical staff as they should be and as a result many “think that the only way that they can assist in the decision-making of an adult with a learning disability is by becoming a welfare deputy”.¹⁴⁴
94. One witness, who subsequently obtained a welfare deputyship for her sister, after a serious accident left her in a coma, described her family’s experience of dealing with health care staff:
- “We did not know the system and were in trauma from the accident so it was hard to effectively represent her in the face of institutional evasion and obstruction. We also had no status with the treating clinicians and the culture within this setting seemed to be to treat families as volatile and untrustworthy—lacking capacity to represent their relatives’ views until proven otherwise. One of the treating clinicians informed me later that it usually took her about a year to get to know a family and decide whether or not to trust their input”.¹⁴⁵
95. According to the Carers Trust and Carers UK, one of the difficulties in challenging the misuse of the Act was the general lack of awareness of its provisions, particularly the best interests decision-making process, among family members and carers.¹⁴⁶ We heard evidence that families were surprised to discover that they were not the decision-maker on behalf of their relative: “many family members still feel they have an inherent right to make decisions on someone else’s behalf; this appears to be particularly evident in families of a person with a degree of learning disability”.¹⁴⁷ Hft, the charity supporting people with learning disabilities and their carers, said that “Parents (or other family members) need to know that, by law, they are no longer decision-maker by default as is often the case when your son/daughter, brother/sister is a child”.¹⁴⁸ Oi Mei Li, Director of the National Family Carer Network, referred to this change as “a complete culture shock” which had “an enormous emotional impact on family carers”.¹⁴⁹ Professor Celia Kitinger and Professor Jenny Kitinger pointed out that “even academic audiences are surprised that next-of-kin cannot make decisions for another adult”.¹⁵⁰ This is borne out by research cited by Compassion in Dying, which indicated that 53% of the public wrongly

¹⁴² Q 129.

¹⁴³ Q 129.

¹⁴⁴ Mencap.

¹⁴⁵ Jenny Kitinger.

¹⁴⁶ Q 128.

¹⁴⁷ Worcestershire County Council and Worcestershire Health and Care Trust integrated Learning Disability Teams.

¹⁴⁸ Hft.

¹⁴⁹ Q 134.

¹⁵⁰ Professor Celia Kitinger (University of York) and Professor Jenny Kitinger (Cardiff University).

- believe they have the legal right to make end of life treatment decisions for their next of kin.¹⁵¹
96. Tussie Myerson, the parent and Court-appointed deputy of a person with “complex and life limiting” conditions who lacked capacity, argued that not enough was being done to inform families about the Act. She stated that “Leaflets are no good” and that there was a need for “a structured ‘marketing campaign’ through hospices, schools, social workers and even Consultant doctors to make parents aware”.¹⁵²
97. Evidence also revealed confusion over who was responsible for making a decision in a best-interests process. North Yorkshire County Council said that greater clarity was needed, and that “the examples given in the code do not reflect the complexity of circumstances that can surround many decisions to be made”.¹⁵³ A joint submission from the London Borough of Hammersmith & Fulham, the Royal Borough of Kensington & Chelsea and the City of Westminster concurred, and suggested that ongoing training and support was needed “to ensure that it is clear who the decision-maker is”.¹⁵⁴ Toby Williamson said that, particularly in complex decisions involving multi-disciplinary teams, “staff were struggling to understand who a decision-maker is and what is the exact decision that was being made”.¹⁵⁵ Evidence from Sense agreed: “in best interests meetings involving more than one agency ... it can be extremely difficult to determine who the decision-maker should be”.¹⁵⁶
98. There were also concerns that a decision-maker could assume too much power, and sometimes on the basis of questionable legal authority. Sheffield Safeguarding Adults Board pointed out that “once a person has been deemed to lack capacity to make a decision they become vulnerable to the opinion of the decision-maker and when those decisions are not reflective of their best interests it often leaves them powerless to challenge”.¹⁵⁷ This was echoed by other witnesses who expressed concern over the use of the ‘general defence’—the term often used to describe sections 5 and 6 of the Act (*Acts in connection with care or treatment* and *Section 5 Acts: limitations*)—which provides protection from liability for carers and others to carry out acts in relation to a person who lacks capacity. The pre-legislative scrutiny committee foresaw problems with these sections, which were at the time entitled ‘the general authority’. They worried that it would wrongly give the “impression that the general authority would be assumed by a single individual who would then take all decisions on behalf of an incapacitated individual”.¹⁵⁸ In response, the Government removed the term ‘general authority’ from the Bill, but concerns have persisted since implementation. Professor Phil Fennell and Dr Lucy Series described the general defence as providing “tremendous discretionary power” which was “not subject to any

¹⁵¹ Compassion in Dying.

¹⁵² Tussie Myerson.

¹⁵³ North Yorkshire County Council.

¹⁵⁴ London Borough of Hammersmith & Fulham, the Royal Borough of Kensington & Chelsea and the City of Westminster.

¹⁵⁵ Q 50.

¹⁵⁶ Sense.

¹⁵⁷ Sheffield Safeguarding Adults Board.

¹⁵⁸ Joint Committee on the Draft Mental Incapacity Bill, *op.cit.*, pages 35 & 36.

routine monitoring”.¹⁵⁹ Liberty expressed concern about the very wide range of decisions which could be made under these sections, combined with a “worrying lack of oversight”.¹⁶⁰

99. The centrality of P at the heart of the best interests process has been given a new impetus by the recent Supreme Court judgment in *Aintree University Hospital Foundation Trust v James*.¹⁶¹ The importance of this judgment, which was the first time the Supreme Court had considered the Mental Capacity Act, was highlighted by the barrister Alex Ruck Keene, who said that Baroness Hale of Richmond had “emphasised that the purpose of the best interests test is to consider matters from the patient’s or from the person’s point of view”.¹⁶² Mr Ruck Keene suggested that “all those who practise in the area will be emphasising that message loud and clear”.¹⁶³ Kirsty Keywood told us that placing greater emphasis on the role of P in the best interests process, while simultaneously diminishing the importance of objective criteria, could achieve a closer alignment with the requirements of the United Nations Convention of the Rights of Persons with Disabilities, since the will, rights and preferences of P should be “the starting point for any kind of determination of what is best for an individual”.¹⁶⁴ This would ensure that genuinely substituted decision-making was limited to a very small number of people who had no way to communicate their wishes.
100. In the social work context much evidence focused on the misuse of the best interests principle in order to justify decisions taken by local authorities about an individual’s care, without carrying out the necessary consultations, and often against the wishes of P and P’s carers. Families believed what they were told: “The social worker said they are using Section 4 of the Mental Capacity Act to do this”.¹⁶⁵ The Mental Health Foundation argued that there was a risk of the best interests principle becoming “a tool to justify decisions to safeguard people”.¹⁶⁶ The case of Steven Neary illustrates this:
- “In our case, a decision was made from very early on—that Steven could not return home and instead [should] be sent to a residential establishment. Neither Steven, myself or any other independent person were involved in that decision. Having made that decision, the [local authority] then launched into proving that Steven did not have the capacity to decide where he wanted to live”.¹⁶⁷
101. The overlapping of best interests decisions with capacity assessments has been noted in research carried out by the Mental Health Foundation, who referred to it as the ‘concertina effect’—a process whereby the steps set out in the principles of the Act are rolled into one, effectively negating the empowering ethos and being led by the outcome decided on by

¹⁵⁹ Professor Fennell and Dr Lucy Series.

¹⁶⁰ Liberty.

¹⁶¹ *Aintree University Hospitals NHS Foundation Trust v James & Ors* [2013] EWCA Civ 65 (01 March 2013).

¹⁶² Q 247.

¹⁶³ Q 247.

¹⁶⁴ Q 36.

¹⁶⁵ Q 260.

¹⁶⁶ Mental Health Foundation.

¹⁶⁷ Mark Neary.

professionals.¹⁶⁸ The impact of resources on such decisions was raised by Nicola Mackintosh (paragraph 65), as was the perception of risk by many other witnesses (see paragraphs 84–89); both are relevant in illustrating the misappropriation of best interests decision-making.

The fifth principle: the least restrictive option

102. The final principle in section 1 of the Act, often referred to as the ‘least restrictive option’, requires that “Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person’s rights and freedom of action”. We received less evidence on this principle specifically, although the evidence we did receive tended to reiterate the themes already identified: the tendency by professionals to protect rather than to empower, the dominance of risk-averse decision-making, the use of the Act to justify decisions already made, and the failure to follow the best interests process and place P at the centre of the decision.¹⁶⁹ The ‘least restrictive option’ principle was raised explicitly in relation to care for dementia patients. Professor Jones referred to research “which showed that 60% or thereabouts of patients with dementia who were admitted to hospital were admitted from their home, but only 30% were discharged back to their home”.¹⁷⁰ This raised the question of whether the least restrictive option in such cases—a return home, with support—was adequately and routinely considered, and the extent to which concerns regarding risk as well as resources were allowed to lead decision-making.

Conclusions and recommendations

103. **We acknowledge the wide-spread support which the Act enjoys among stakeholders. It is described in unusually enthusiastic language. It is disappointing therefore that the implementation of the Act has yet to receive the same acclaim.**
104. **The empowering ethos of the Act has not been widely implemented. Our evidence suggests that capacity is not always assumed when it should be. Capacity assessments are not often carried out; when they are, the quality is often poor. Supported decision-making, and the adjustments required to enable it, are not well embedded. The concept of unwise decision-making faces institutional obstruction due to prevailing cultures of risk-aversion and paternalism. Best interests decision-making is often not undertaken in the way set out in the Act: the wishes, thoughts and feelings of P are not routinely prioritised. Instead, clinical judgments or resource-led decision-making predominate. The least restrictive option is not routinely or adequately considered. This lack of empowerment for those affected by the Act is underlined by the fact that many responsible for its**

¹⁶⁸ Williams, V., Boyle, G., Jepson, M., Swift, P., Williamson, T., Heslop, P., *Making Best Interests Decisions: People and Processes*, January 2012, page 50
http://mentalhealth.org.uk/content/assets/PDF/publications/best_interests_report_FINAL1.pdf.

¹⁶⁹ POhWER; Age UK Cheshire Advocacy; The College of Social Work; South Essex Partnership University NHS Foundation Trust; Solicitors for the Elderly.

¹⁷⁰ Q 33.

implementation continue to consider it as part of the safeguarding agenda.

- 105. The presumption of capacity, in particular, is widely misunderstood by those involved in care. It is sometimes used to support non-intervention or poor care, leaving vulnerable adults exposed to risk of harm. In some cases this is because professionals struggle to understand how to apply the principle in practice. In other cases, the evidence suggests the principle has been deliberately misappropriated to avoid taking responsibility for a vulnerable adult.**
- 106. The rights and responsibilities of the different stakeholders which are properly conferred under the Act are largely unknown. This makes the effective exercise of those rights, and the proper discharge of those responsibilities almost impossible.**
- 107. The general lack of awareness of the provisions of the Act has allowed prevailing professional practices to continue unchallenged, and allowed decision-making to be dominated by professionals, without the required input from families and carers about P's wishes and feelings.**
- 108. A fundamental change of attitudes among professionals is needed in order to move from protection and paternalism to enablement and empowerment. Professionals need to be aware of their responsibilities under the Act, just as families need to be aware of their rights under it. We consider how this can be achieved in the next chapter.**
- 109. In the first instance we recommend that the Government address as a matter of urgency the issue of low awareness among those affected, their families and carers, professionals and the wider public.**
- 110. We reiterate that our findings on the implementation of the core principles concern the operation of the Act principally in health and social care settings. We have very little evidence on the use of the core principles in other sectors. However, given the poor levels of knowledge and understanding in the sectors on which the Government targeted its implementation programme, we have no reason to believe that the Act is operating well in other areas. We recommend the Government consider urgently the need for assessing usage of the core principles across the range of decisions affecting people lacking capacity, including in sectors such as banking and policing.**

CHAPTER 4: ADDRESSING POOR IMPLEMENTATION OF THE ACT

111. In light of the evidence regarding the poor implementation of the Act, we sought to understand who had responsibility for it, now that the Government's implementation programme had ceased. The answer appeared to be that no-one had specific or overall responsibility for the Act. Three witnesses summed up the dilemma: Dr Ruth Allen observed that "there is something about the way the MCA is regulated, monitored and the governance around it that is weak".¹⁷¹ The Lancashire County Council DoLS team concurred; whereas the Act "should underpin and influence everything we do ... it is often seen as a bit of an 'add on'".¹⁷² The British Institute of Learning Disabilities pointed to the apparent lack of enforcement, since there appeared "to be no structure by which non-compliance with [the Act] is currently being highlighted or addressed".¹⁷³
112. One reason for this may be the wide range of bodies with varying levels of responsibility for implementation and enforcement of the Act. They include the Care Quality Commission, the Equality and Human Rights Commission, the Local Government Ombudsman, the Parliamentary and Health Service Ombudsman and the professional regulators for the health and care professions, i.e. the General Medical Council, the Nursing and Midwifery Council and the Health and Social Care Professions Council. We also heard evidence from the medical Royal Colleges about their role in setting and maintaining standards in health care. Commissioners of services—specifically local authorities, clinical commissioning groups and NHS England—were frequently cited as central to better implementation. The Social Care Institute for Excellence was cited as a source of guidance and many witnesses pointed to the importance of the voluntary sector in disseminating information to service users and their families. The wide range of bodies involved in implementing the Act, would be felt most acutely by individuals responsible for complying with it, since they will frequently be subject to more than one regulatory regime. For example, a nurse would be subject to inspection by the CQC, and regulation by the Nursing and Midwifery Council—as well as receiving guidance from professional bodies such as the Royal College of Nursing.
113. **Despite the many organisations involved in implementing the Act, it appears that no single body has overall responsibility for it. This may help to explain the patchy implementation of the Act. Without central ownership and co-ordination of implementation, the very positive benefits of the legislation will not be realised. A permanent, proactive, dedicated and independent resource with responsibility for promoting awareness, understanding and good practice across affected sectors is needed to ensure a step change.**
114. **We recommend that overall responsibility for implementation of the Mental Capacity Act be given to a single independent body. This does not remove ultimate accountability for its successful implementation**

¹⁷¹ Q 139.

¹⁷² Lancashire County Council DoLS Team.

¹⁷³ British Institute of Learning Disabilities.

from Ministers, but it would locate within a single independent body the responsibility for oversight, co-ordination and monitoring of implementation activity across sectors, which is currently lacking. This new responsibility could be located within a new or an existing body. The new independent body would make an annual report to Parliament on the progress of its activities.

115. **The proposed independent oversight body would not act as a regulator or inspectorate, but it would work closely with such bodies which have those responsibilities in relation to the Mental Capacity Act. The body should act as a support to professionals required to implement the Act.**
116. **The composition of the new independent body should reflect the professional fields within which the Act applies, and it should contain professional expertise. It should also include representation from those directly affected by the Act as well as their families and carers. This is vital to ensure credibility. Other key features of the independent body will be continuity, expertise, accountability and accessibility.**
117. **The Mental Capacity Act Steering Group is a welcome first step in this direction, and we recommend that it be tasked with considering in detail the composition and structure of the independent oversight body, and where this responsibility would best be located. The former Mental Health Act Commission strikes us as an effective, cost-efficient and credible model from which lessons may be learned.**
118. We make further recommendations concerning the responsibilities of the proposed independent body throughout this and subsequent chapters.

Oversight of organisations

119. Although the Code of Practice specifically identifies the Parliamentary and Health Service Ombudsman (PHSO) and the Local Government Ombudsman as routes for complaint, only the PHSO submitted evidence and very few submissions discussed its role. Instead, the Care Quality Commission (CQC) was the most frequently cited inspectorate. This is unsurprising, given the role of the CQC to inspect and register health and social care services in England, and its statutory role to monitor and report on the implementation of the deprivation of liberty safeguards.¹⁷⁴
120. Officials and Ministers placed considerable emphasis on the role of the CQC in driving better implementation of the Mental Capacity Act.¹⁷⁵ The CQC explained that while it had “no direct powers to enforce the MCA,” the Health and Social Care Act 2008 had very similar requirements in relation to patient involvement, choice, decision-making and care planning.¹⁷⁶ Therefore failure to implement the Mental Capacity Act could be taken into account when assessing compliance with the Health and Social Care Act, and could lead to regulatory and enforcement action such as a warning notice or

¹⁷⁴ The Mental Capacity Act (Deprivation of Liberty: Monitoring and Reporting; and Assessments – Amendment) Regulations 2009, laid under paragraph 162 of schedule A1 of the Mental Capacity Act 2005.

¹⁷⁵ QQ 19, 21 and 314-315.

¹⁷⁶ Care Quality Commission.

- prosecution.¹⁷⁷ Despite not having a statutory role in relation to local authorities when acting as supervisory bodies, the CQC was keen on promoting a “collaborative approach based on sharing good practice”.¹⁷⁸ However, where necessary it had contacted individual authorities to remind them of their responsibilities.¹⁷⁹
121. We were told of the positive impact which the regulator could have on improving performance: Elmari Bishop, lead for the Mental Capacity Act at the South Essex Partnership University NHS Foundation Trust, described how a few bad inspections gave “the final push” to gaining support internally to far-reaching changes in implementing the Act at the Trust (see Box 6, A case study in what works).¹⁸⁰
122. The College of Social Work, however, summed up the views of many witnesses when it said that: “while acknowledging that theoretically the CQC was well-placed to regulate, some felt that staff at the CQC had insufficient knowledge of the MCA to act appropriately”.¹⁸¹ Age UK and Kate Beynon, a best interests assessor in Northamptonshire County Council suggested that CQC inspectors lacked sufficient knowledge of the safeguards.¹⁸² The Royal College of Nursing argued that “the CQC could do more within their inspection routines to examine the scope of how the MCA is used by health professionals”.¹⁸³
123. Concern was expressed that the CQC’s role in relation to the deprivation of liberty safeguards was limited to monitoring and reporting.¹⁸⁴ Alzheimer’s Society argued that there was a need for greater policing of local authority responses to authorisation requests,¹⁸⁵ which was not currently part of the role of the CQC.¹⁸⁶ BASW agreed that the CQC’s inspection role should be extended to cover the supervisory body functions of local authorities.¹⁸⁷ The Law Society also argued for increased powers for the CQC,¹⁸⁸ and the Judith Trust wanted to see parity with the powers of the CQC under the Mental Health Act.¹⁸⁹ The CQC itself, though, felt that it had sufficient powers, as did the Government.¹⁹⁰ Dr Regnard, a consultant in palliative care medicine suggested that “additional powers would not be required if non-compliance was exposed and it was made clear how and why this breaches current legislation”.¹⁹¹

¹⁷⁷ *Ibid.*

¹⁷⁸ *Ibid.*

¹⁷⁹ *Ibid.*

¹⁸⁰ Q 265.

¹⁸¹ The College of Social Work.

¹⁸² Age UK; Kate Beynon PSW/BIA/AMHP (Safeguarding Adults Team, Northamptonshire County Council).

¹⁸³ Royal College of Nursing.

¹⁸⁴ Wigan Family Welfare; Irwin Mitchell LLP.

¹⁸⁵ Alzheimer’s Society.

¹⁸⁶ Care Quality Commission.

¹⁸⁷ British Association of Social Work.

¹⁸⁸ The Law Society.

¹⁸⁹ The Judith Trust.

¹⁹⁰ Ministry of Justice.

¹⁹¹ Claud Regnard FRCP (Consultant in Palliative Care Medicine, St Oswald’s Hospice).

124. There was some suggestion that the CQC recognised the criticisms levelled at it. Changes were expected to the regulations which set out the standards against which the CQC inspects, and this presented an opportunity to ensure “that the principles of the [Mental Capacity Act] sit at the heart of CQC’s understanding of care quality in the new regulatory models”.¹⁹² David Behan, Chief Executive of the CQC, promised us he would “ensure that mental capacity is built into the way that we conduct our inspections—whether of hospital services, community healthcare services or ... adult social care services”.¹⁹³ Since we took evidence from Mr Behan the Department of Health has published a consultation on proposals to change the CQC registration regulations.¹⁹⁴ None of our witnesses referred to this document as it was published after our deadline for submissions. However, in light of the evidence we have received we believe it will be important for the standards to reflect, as far as possible, the empowering ethos of the Act, with a particular emphasis on supported decision-making.
125. We note the publication on 15 January by the CQC of its annual report into the operation of the deprivation of liberty safeguards.¹⁹⁵ In his foreword Mr Behan acknowledged that “the Act is still not understood and implemented consistently across health and social care services. This is not good enough”.¹⁹⁶ The report conceded that “it is difficult to avoid the conclusion that some people in care homes and hospitals may be subject to restraint without the full protection of the law”.¹⁹⁷ In response the CQC has committed itself to a new approach in ensuring that health and care providers comply with the Mental Capacity Act. It has undertaken to capture the experiences of those directly affected by deprivations of liberty, improve training of its inspectors, build on its relationships with local authorities to improve compliance, and promote better awareness and understanding of the safeguards in care homes and hospitals. The three Chief Inspectors “will ensure that MCA principles are hardwired into our new model for regulation and inspection in all services registered with CQC”.¹⁹⁸
126. **It is clear that the CQC has not used its existing powers to best effect to ensure that the requirements of the Mental Capacity Act are met in practice. We welcome the recognition by the CQC that a new focus on the Act is required in the way it regulates and inspects services.**
127. **We recommend that the standards against which the CQC inspects should explicitly incorporate compliance with the Mental Capacity Act, as a core requirement that must be met by all health and care providers. Meeting the requirements of the empowering ethos of the Act, and especially in terms of actively enabling supported decision-**

¹⁹² Care Quality Commission.

¹⁹³ Q 197.

¹⁹⁴ Department of Health, *Introducing Fundamental Standards*, consultation on proposals to change CQC registration regulations, 23 January 2014:

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/274715/Introducing_Fundamental_Standards_-_a_Consultation.pdf.

¹⁹⁵ Care Quality Commission, *Monitoring the use of the Mental Capacity Act Deprivation of Liberty Safeguards in 2012/13*, January 2014: http://www.cqc.org.uk/sites/default/files/media/documents/dols_2014.pdf.

¹⁹⁶ *Ibid.*

¹⁹⁷ *Ibid.*

¹⁹⁸ *Ibid.*

making, must be given equal status with the appropriate use of the deprivation of liberty safeguards, or their replacement provisions.

Training and oversight of professionals: the role of professional regulators and medical Royal Colleges

128. In health and care settings the medical Royal Colleges, and the professional regulators for the different health and care professions, should be well placed to influence practice. We heard from the Academy of Medical Royal Colleges, the Royal College of GPs, the Royal College of Psychiatrists, the College of Emergency Medicine, the General Medical Council and the Health and Care Professions Council. With the exception of the Royal College of Psychiatrists, we were not convinced that the Mental Capacity Act was a priority for any of these bodies and this was reflected in the evidence.
129. While the professional regulators, such as the GMC, have important regulatory functions and the ability to sanction those who fail to meet professional standards, they also have a vital education and standard setting role. Mr Paul Buckley, Director of Education and Standards at the GMC, summed up the regulator's function as "to protect, promote and maintain the health and safety of the public by ensuring proper standards in the practice of medicine".¹⁹⁹ Mr Buckley explained that the Act featured in the GMC's work on standards, education, outreach and ultimately their fitness to practice determinations.²⁰⁰ The Health and Care Professions Council said that while the vast majority of professionals met the high standards required throughout their professional careers, lessons could be learned from those that did not, and from feeding these lessons back into the universities and the professional bodies to improve standards.
130. The Royal Colleges told us they played an active role in supporting health and care professionals to understand and implement the Act. Professor Bailey, representing the Academy of Medical Royal Colleges, told us that the Act did appear in the current foundation programme curriculum, but that she had "had a relook at it, and I do think the emphasis is on mental health. There could be a stronger emphasis on capacity".²⁰¹ The Royal College of GPs told us that their core curriculum and membership examination included details of the Act, "along with clinical issues associated with patients with impaired cognition and how these might be addressed in practice".²⁰² In addition, we were told that the Royal College of GPs had developed proposals to extend GP training which, if implemented, could "ensure that future GPs are even better equipped to comply with the Act".²⁰³ The additional training was expected to include "further measures to help to train incoming GPs to effectively communicate with patients with communication difficulties, involve carers, relatives and friends, within the bounds of confidentiality, to develop professional judgment around lack of capacity and long-term care planning".²⁰⁴ Dr Apakama of the College of

¹⁹⁹ Q 210.

²⁰⁰ Q 210.

²⁰¹ Q 153.

²⁰² Royal College of General Practitioners.

²⁰³ *Ibid.*

²⁰⁴ Q168.

Emergency Medicine told us that the Act was part of the curriculum and formally tested at Membership and Fellowship examinations.²⁰⁵

131. Dr Chalmers, of the Royal College of Psychiatrists, described the work of her College on the Mental Capacity Act, which was, perhaps unsurprisingly, centred on mental health. She told us that the College had been working with the CQC to look at “what does “good” mean in clinical practice and setting standards”²⁰⁶ including in relation to the Mental Capacity Act, but that this had proved to be a challenge “because, unlike the Mental Health Act, where there are clear things that you can count and then follow up—for example the number of detentions ... —the Mental Capacity Act is more about a philosophy of care and a spirit of enablement”.²⁰⁷
132. Mencap told us they had undertaken work with Royal Colleges and health care professionals to develop a charter for Clinical Commissioning Groups that spelt out “the nine key activities that all health care professionals should do to ensure that there is equal access to health for people with learning disabilities”, one of which related to the Act.²⁰⁸ The Department of Health said that “the Royal Colleges, particularly the Royal College of Psychiatrists, have all been very heavily involved in training their relevant membership groups”.²⁰⁹
133. However, the evidence we set out in chapter 3 suggests that such activities have been insufficient to embed the Act in day-to-day practice. We note that GPs, in particular, were identified as having a poor understanding of the Act. Sense, the charity for deaf-blind people, reported an incident of a GP who attempted to charge for the additional time taken to explain to the person what was involved in a blood test to obtain consent.²¹⁰ Safeguarding Essex said that “GPs seem reluctant to accept that the legislation appertains to them as practitioners and frequently appear to either ignore it or refer to Social Care for guidance”.²¹¹ We already noted the case study examples provided by the CIPOLD team where failure by GPs to follow the Act had led to avoidable deaths (paragraph 77). Dr Heslop, principal investigator of CIPOLD, argued that training should be targeted at GPs as well as other non-specialist health service practitioners.²¹² The lack of familiarity of health care staff, including GPs, with advance decisions to refuse treatment is considered in chapter 5; we note some concerns in paragraph 195.
134. Some witnesses questioned the extent to which the Royal Colleges and the professional regulators were fulfilling their roles in relation to the Act. Age UK argued that:

“There is a case for professional health and care regulators taking a greater role in relation to the MCA. For example there is reference to the Act included within the GMC’s ‘Good Medical Practice’ guidance

²⁰⁵ Q 153.

²⁰⁶ *Ibid.*

²⁰⁷ *Ibid.*

²⁰⁸ Mencap.

²⁰⁹ Q 6.

²¹⁰ Q 48.

²¹¹ Safeguarding Essex.

²¹² Q 72.

but we would suggest that it could also be part of the revalidation process for doctors”.²¹³

135. Dr Claud Regnard argued for the Royal Colleges and professional regulators to emphasise the central role of the Act in decision-making, including the importance of determining best interests as set out in the Act, as distinct from clinical best practice judgments. He also called for compliance with the Act to be a requirement of practice and continued employment as a health or care professional.²¹⁴ Mencap expressed disappointment at “the failure of the GMC to take to tribunal at least three cases that we have referred to them where doctors have ... failed against the Mental Capacity Act”.²¹⁵ This had resulted in unlawful actions that “do not seem to be met with appropriate sanctions,”²¹⁶ leaving the impression that professional regulators were not taking failures to adhere to the Act seriously enough.²¹⁷
136. Under section 1 of the Health and Social Care Bill 2012 the Secretary of State for Health is required to promote a comprehensive health service designed to secure improvement in a) the physical and mental health of the people of England, and b) the prevention, diagnosis and treatment of physical and mental illness. This recognition in statute of the equal responsibility of the state towards physical and mental health has been termed ‘parity of esteem’. We are concerned that this commitment is undermined by the current difficulties in recruiting medical students into academic psychiatry. We note the report by the Academy of Medical Sciences, ‘*Strengthening Academic Psychiatry*’, published in March 2013, which identified the barriers to recruiting trainee academic psychiatrists. Professor Sue Bailey, President of the Royal College of Psychiatrists, said in response to the report’s findings, that strengthening psychiatry as a speciality was central to delivering parity between physical and mental health.²¹⁸ Increasing research into mental illness was considered an important target by the Academy of Medical Sciences—although mental illness accounts for 15% of the disease burden, mental health research accounts for only 5%-6% of the UK’s total health research spending.²¹⁹ Not unrelated to the barriers to recruiting students into academic psychiatry is the worrying decline in academic posts in psychiatry—the overall number of which has fallen 26.8% since 2000.²²⁰ Although not everyone who lacks capacity has mental health problems, the poor implementation of the Mental Capacity Act by health professionals is, to some extent, symptomatic of a wider marginalisation of mental health issues. We therefore support efforts by the Academy of Medical Sciences and the Royal College of Psychiatrists to achieve parity of esteem, not least by ensuring adequate training, research and leadership in psychiatry.

²¹³ Age UK.

²¹⁴ Claud Regnard FRCP (Consultant in Palliative Care Medicine, St Oswald’s Hospice).

²¹⁵ Q 89.

²¹⁶ *Ibid.*

²¹⁷ Mencap.

²¹⁸ Royal College of Psychiatry press release, *College responds to strengthening academic psychiatry report*, 29 March 2013:

<http://www.rcpsych.ac.uk/mediacentre/pressreleases2013/strengtheningacademicpsychiatr.aspx>.

²¹⁹ The Academy of Medical Sciences, *Strengthening Academic Psychiatry in the UK*, March 2013, p9: http://issuu.com/acmedsci/docs/academy_psychiatryfinal.

²²⁰ *Ibid.*

137. **The Act needs a higher profile among professionals in order to be properly understood and effectively implemented. The medical Royal Colleges and professional regulators have a responsibility to play their part in promoting best practice through standard setting, training, awareness-raising and enforcement.**
138. **We recommend the Government work with professional regulators and the medical Royal Colleges to ensure that the Act is given a higher profile. This work should emphasise the empowering ethos of the Act, and the best interests process as set out in section 4 of the Act. In future, we would expect the responsibility for this to sit with the independent oversight body.**
139. **In particular, we recommend that the GMC:**
- **ensure that there is leadership in psychiatry within all medical schools in order to give a higher profile to mental health;**
 - **place proper emphasis on the Mental Capacity Act in its publication ‘Good Medical Practice’;**
 - **enhance training on the Mental Capacity Act in all post-graduate education, especially for GPs.**
140. **The proposed fourth year of training for GPs provides an opportunity to embed and enhance understanding of the Mental Capacity Act with this group of practitioners. We recommend that the Government supports the proposal in light of the vital role which GPs play in providing health care in the community.**
141. **Consistency in training and oversight of professionals is essential. Whatever body is given responsibility for the implementation of the Act will have a vital role in co-ordinating the response of the medical Royal Colleges and professional regulators to ensure a shared understanding of legal obligations under the Act is used by all.**
142. **We expect that the existence of an independent oversight body with responsibility for implementation of the Act will act as a spur to the medical Royal Colleges and the professional regulators in taking forward work to raise the profile of the Mental Capacity Act and ensure compliance.**

Commissioning

143. **The role of commissioners of health and social care in identifying and acting on poor practice was highlighted by the Department of Health²²¹ and Dr Margaret Flynn, former Chair of the serious case review into Winterbourne View.²²² The British Institute of Human Rights argued that commissioners of services are integral to ensuring the Act is correctly implemented and applied in practice. For this to happen commissioners needed to be “properly trained and equipped”²²³ to ensure their decisions**

²²¹ Q 13.

²²² Q 57.

²²³ British Institute of Human Rights.

and practices supported people who lacked capacity. Mencap made the same argument.²²⁴

144. The CQC reported that commissioners and providers had a low understanding of the Act.²²⁵ However, we heard evidence of good practice in some local authority areas. The Association of Directors of Adult Social Services (ADASS) endorsed work underway in the West Midlands. Lorraine Currie, representing ADASS West Midlands Regional DoLS Leads group, described work that embedded the Act into contractual requirements with care providers. As part of this, free training was provided to care home staff. High levels of staff turnover in the care sector meant that training was provided to “a couple of thousand people each year from hospitals and care homes as well as the local authority”.²²⁶ Ongoing training and support was seen as important because “the Mental Capacity Act is ever changing. Our understanding of it is ever changing, and it evolves in different directions, so we offer them as much support as we can in order to ensure best practice”.²²⁷ This practice was not isolated—a team of best interests assessors from Greenwich reported free training being increasingly provided by commissioners, with local authority teams gradually taking on a greater role in ensuring care providers understood and applied the Act, including the deprivation of liberty safeguards.²²⁸

145. Terry Dafter of ADASS expanded on the role of commissioners in monitoring good practice once contracts were in place:

“you do have to build it into your contracting arrangements; you have to make sure people are trained within that home and that there is leadership from the top—that the manager and the deputy manager are well trained and well versed in the Act. You have to check out the number of referrals you are getting per home and worry about a home that you do not necessarily get any referrals from and equally worry about ones where there is perhaps an overzealous application of the Act. You start to ask the people who monitor your contracts to bear those figures in mind along with other reporting figures that we take around the sector”.²²⁹

146. The role of commissioners in driving better performance was also identified by Elmari Bishop in relation to the experience of the South Essex Partnership University NHS Foundation Trust:

“Our commissioners ... also caught on to the whole idea of the Mental Capacity Act and DoLS, and they started asking us every three months to report on what we were doing in that regard: what training we were doing, how many assessments we had done, what we had done to improve staff understanding, how we were monitoring it, and how often we were auditing it”.²³⁰

²²⁴ Mencap.

²²⁵ Care Quality Commission.

²²⁶ Q 179.

²²⁷ Q 179.

²²⁸ Royal Borough of Greenwich, Best Interests Assessors Forum.

²²⁹ Q 179.

²³⁰ Q 265.

147. The importance of health sector commissioners taking on this role was touched on by Dr Heslop.²³¹ The CIPOLD inquiry recommended that NHS England and clinical commissioning groups ensure that they have adequate oversight of “the appropriate Mental Capacity Act safeguarding arrangements” and that “together with regulators they must enforce the Act”.²³²
148. Officials from the Department of Health were clear that NHS England had a responsibility, through the NHS Mandate, to “demonstrate progress in continuing to improve safeguarding practice in the NHS. This includes improving the understanding and implementation of the Mental Capacity Act”.²³³ However, the new (or ‘refreshed’) Mandate published in November 2013 still did not contain reference to the Mental Capacity Act. When questioned on this the Minister for Care and Support pointed to work underway to further parity of esteem between mental and physical health services. However, he acknowledged that it would have been helpful to have referred to implementation of the Mental Capacity Act as a priority.²³⁴
149. NHS England put it to us that they had “put leadership for safeguarding and the Mental Capacity Act at every level of the system” in the recent changes to NHS commissioning. This involved the nomination of Mental Capacity Act and safeguarding leads in each of the 211 clinical commissioning groups, a medical director with responsibility for safeguarding in each of the 27 area teams, directors of nursing responsible for safeguarding in partnership with a medical director in each of the four regions, and national level accountability for safeguarding and the Mental Capacity Act vested in the Chief Nursing Officer.²³⁵ These structures chime with the CIPOLD inquiry recommendations, and the Care Quality Commission specifically welcomed the requirement that clinical commissioning groups have a named lead on the Act.²³⁶
150. Nevertheless, two features of this description cause concern. First, it demonstrates the extent to which the Act is intrinsically linked with safeguarding within NHS systems and structures. This is disconcerting in light of the evidence that we received about the imbalance between empowerment and paternalism in some health care settings. Second, the description provided is of structures rather than practice. NHS England told us “We have done some rapid appraisals about where we are in terms of capability, confidence, training, etc,”²³⁷ with a number of Clinical Commissioning Groups but these appraisals did not appear to have provided robust evidence. There appeared to be, in general, an absence of data concerning actual practice on the ground, and we regret this. We note and endorse the recommendation by the CQC in its report on the deprivation of liberty safeguards 2012/2013, that NHS England should include expectation

²³¹ Q 56.

²³² *Ibid.*

²³³ Ministry of Justice and Department of Health.

²³⁴ Q 322.

²³⁵ Q 221.

²³⁶ Q 209.

²³⁷ Q 221.

of the effective use of the deprivation of liberty safeguards into standard contracts for providers.²³⁸

151. **Commissioning has a vital role to play in ensuring that the Act is implemented and complied with in practice. We have noted examples of how commissioners can promote good practice through support and contractual requirements. We recommend that the Government, and subsequently the independent oversight body, work with the Association of Directors of Adult Social Services and NHS England to encourage wider use of commissioning as a tool for ensuring compliance.**
152. **We recommend that the ‘refresh’ of the NHS Mandate in 2014 include requirements explicitly connected to the implementation of the Mental Capacity Act, based on evidence of good practice gathered from Clinical Commissioning Groups.**
153. **We further recommend that NHS England and ADASS take steps to ensure that the empowering ethos of the Mental Capacity Act is understood and given visibility within commissioning, even where this may appear to conflict with the safeguarding agenda.**

Access to advice and information on the MCA

154. Although we recognise that improving understanding of the Act requires more than improved guidance, it was noticeable how frequently witnesses called for improved access to information, despite the range of sources already available. The original Code of Practice to the Mental Capacity Act was published in 2007, with a supplementary Code for the deprivation of liberty safeguards following in 2008. Other sources of information include the Social Care Institute for Excellence, the Office of the Public Guardian and the Court of Protection. In addition, many local authorities have produced tailored information, as have many voluntary sector organisations.

The Codes of Practice

155. Several witnesses argued that the Codes were out of date, calling for them to be updated in light of experience and case law.²³⁹ Concern was also expressed that the current Codes are unwieldy,²⁴⁰ and a number of witnesses advocated merging the main Code and the supplementary Code for the deprivation of liberty safeguards into a single, accessible, Code of Practice.²⁴¹ Mencap proposed tailored codes of practice for particular audiences, similar to the various Codes of Practice that accompany the Equality Act 2010, to make them relevant and accessible to practitioners in different fields. It also called for the Code to be made accessible to people directly affected by the Act, in order to bring it into line with the UK’s commitments under the UN Convention on the Rights of Persons with Disabilities.²⁴² This appeared to be supported by evidence from Mr Simon Cramp, an adult with learning

²³⁸ Care Quality Commission, *Op. Cit.* January 2014, p 51.

²³⁹ British Psychological Society; British Association of Social Workers; London Borough of Newham Adults Social Care; London MCA/DoLS Network.

²⁴⁰ Housing and Social Care Services, London Borough of Camden.

²⁴¹ Mind; British Association of Social Workers.

²⁴² Mencap.

disabilities, who previously gave evidence to the pre-legislative scrutiny committee. In his view the Codes of Practice were not used “because they are big documents with lots of detail”.²⁴³ He suggested that instead “perhaps the key areas of the act that are used most should be a pocket book that is issued at the government expense in hard copy”.²⁴⁴

156. Unsurprisingly, given the evidence concerning the failure to implement the principles of the Act, many suggestions focused on improving practice in relation to those principles. As well as the use of more sophisticated case examples to assist with assessing capacity suggested by Dr Heslop, others suggested the functional approach to capacity could be promoted through the Code, as could “the concept of a capacitous unwise decision”.²⁴⁵ BASW suggested using the Code to ensure the appropriate balance between adult safeguarding and the Act.²⁴⁶ More specifically, Mencap called for greater clarity about the meaning of ‘serious medical treatment’. It argued that it should include non-emergency Do Not Resuscitate Orders, as well as any decision taken not to treat or investigate.²⁴⁷
157. Despite these suggestions, many witnesses praised the Code of Practice, which the British Medical Association described as “clear, practically-oriented and readable”.²⁴⁸ The Hft’s Family Carer Support Service said that “The Code of Practice is a long document, but it is very well written and offers lots of good examples of how the Act should work in practice”.²⁴⁹
158. Reviewing the Code of Practice was not in itself considered an answer to poor practice. The Department of Health acknowledged that “We could review the code of practice and the Act and spend a lot of resources and time doing that and not make one jot of difference to people on the ground”.²⁵⁰ Irwin Mitchell LLP argued that the reason that the principles were sometimes misunderstood was because the Code of Practice was rarely read “even by social workers, GPs and other practitioners”.²⁵¹ This appeared to be supported by evidence from the GMC that they were working on providing information in a simpler way, rather than “presenting doctors with a tome on the Mental Capacity Act”.²⁵² Clearly, the information needs of many of those who are affected by the Act, either professionally or personally, are not being met by the Codes.
159. **A wide range of audiences require information on the Act, ranging from medical practitioners to local authorities, legal professionals, families, carers and people who may lack capacity. Current methods of provision, principally the Codes of Practice, are not meeting the needs of all concerned.**

²⁴³ Simon Cramp.

²⁴⁴ *Ibid.*

²⁴⁵ Professor Julian Hughes, Professor John Bond, Dr Helen Greener, Dr Stephen J. Louw, Marie Poole, Professor Louise Robinson and Charlotte Emmett.

²⁴⁶ British Association of Social Workers.

²⁴⁷ Mencap.

²⁴⁸ British Medical Association.

²⁴⁹ Hft.

²⁵⁰ Q 12.

²⁵¹ Irwin Mitchell LLP.

²⁵² Q 211.

160. **We do not believe that a standard review of the Code of Practice is adequate to meet the information needs identified. A broader approach to meeting the diverse needs is required, with the possibility of several tailored resources being designed for different audiences. Some of these resources could be provided exclusively online in order to be updated in line with case law.**
161. **We recommend that, in the first instance, the Mental Capacity Act Steering Group give consideration to how the specific information needs of the different groups affected by the Act can best be met. We recommend that the Steering Group take into account the needs of different audiences for different types of information: for example, legal practitioners will be interested in latest developments in case law; a carer may need a brief summary of their responsibilities under the Act; a person lacking capacity may need their rights presented in an accessible format. In future, ensuring the regular review of such information resources would be the responsibility of the independent oversight body.**
162. **It will be important for consistent information to be provided across professional groups and sectors, including those outside health and social care. The independent oversight body which we recommend should in future co-ordinate between regulators and professional bodies to ensure a common understanding of the Act.**

BOX 6

A case study of what works

The submission from the South Essex Partnership University NHS Foundation Trust (SEPT) described the experience of changing the practice and culture within a single Trust in relation to the Mental Capacity Act. The Trust had faced the potential risk of substantial damages as a result of possibly illegal detentions due to a failure to apply the deprivation of liberty safeguards.²⁵³ Following an improvement plan there was evidence of an increase in activity under the Act of 403%, and in applications under the deprivation of liberty safeguards of 1408%.²⁵⁴ While recognising that more work needed to be done to improve the quality of implementation, the Trust told us that:

“In our organisation we have witnessed exceptionally good practice in this area, which provides concrete proof that, if applied correctly, the MCA can really make a difference and achieve its aims to the benefit of some of the most vulnerable people in society”.²⁵⁵

Emphasising the importance of both leadership and management of cultural change, Elmari Bishop, the lead for the Act in the Trust, explained to us the process for implementing a two-year action plan, starting in August 2011.

The action plan included the re-writing of policies and an intensive training and support programme rolled out across the organisation, approved and supported by the Executive Team. Support from the Board of Directors and allocation of resources was not, in itself, sufficient to overcome resistance

²⁵³ Q 266.

²⁵⁴ The South Essex Partnership University NHS Foundation Trust (SEPT).

²⁵⁵ *Ibid.*

from staff who felt that their professional decision-making abilities were being challenged. Implementation of the Act was not simply about implementing new legislation, it was about “managing change, managing resistance to change and getting support from all levels.” They began by explaining the Act in terms professionals understood, such as consent to treatment and the legal authority to keep a person on the ward and provide treatment. They then gained support from different professional groups: “as soon as we got our medical director and some of the key doctors in our organisation on board, they started to drive the message forward.” This support was crucial to achieving change. Equally important was the impact of “a few bad CQC inspections” and increased attention from commissioners to the action being taken.²⁵⁶

The Trust told us it was continuing its work, with the next phase focusing on implementation of the Act in community settings.

²⁵⁶ Q 265.

CHAPTER 5: ADVOCACY AND ADVANCE PLANNING

163. The general principles enshrined in section 1 of the Act were intended to underpin a shift in public attitudes and practice. But the Act also makes specific provision to facilitate decision-making by or on behalf of people who may lack capacity. These are the structures designed to enable the views and wishes of P to be taken into account when P lacks capacity to make decisions. This chapter considers their implementation.

Independent Mental Capacity Advocates

164. The Act created the role of ‘Independent Mental Capacity Advocate’ (IMCA). In certain circumstances the Act requires that an IMCA is provided, for example where serious medical treatment or accommodation in a hospital or a care home is being proposed for a person who lacks capacity and has no-one to speak on their behalf. Where an application is being made for an authorisation under the Deprivation of Liberty Safeguards an IMCA must be appointed if there is not an appropriate person to consult. Local authorities have discretionary powers to appoint IMCAs in cases of care reviews or adult protection.

165. The creation of the IMCA role was welcomed: “It has ensured that people who lack capacity have had their voice heard and that where appropriate decision makers have been challenged regarding their proposed decisions”.²⁵⁷ The British Institute for Learning Disabilities referred to the role as providing “a safeguard and a greater voice for thousands of people in decisions that are fundamentally important”.²⁵⁸ Local authorities appeared to welcome the IMCA’s role “in both reinforcing the appropriateness of decisions or in providing alternative suggestions and challenge to support the achievement of a least restrictive alternative”.²⁵⁹ BASW commented that “IMCAs have a good reputation and their reports on best interest decisions are respected”.²⁶⁰ At its best, the role of the IMCA was “a force for ensuring the dignity and rights of individuals who find themselves in contact with powerful and confusing systems”.²⁶¹

166. However, the wide variation in referral rates to IMCA services had “reduced the impact that could have been made”.²⁶² We note the fifth report by the Department of Health on the IMCA Service,²⁶³ published in February 2013, which highlighted wide disparities in instruction rates across different regions. The report concluded that “it is likely that in some areas the duties under the MCA are still not well embedded. The duty to refer people who are eligible to IMCAs is still not understood in all parts of the health and

²⁵⁷ Bracknell Forest Council.

²⁵⁸ British Institute of Learning Disabilities.

²⁵⁹ Brighton and Hove City Council. Also: Bracknell Forest Council; MCA and MCA DoLs’ Team of Cambridgeshire County Council; West Sussex County Council.

²⁶⁰ British Association of Social Workers.

²⁶¹ British Institute of Learning Disabilities.

²⁶² *Ibid.*

²⁶³ Bonnerjea, L. *The Fifth Year of the Independent Mental Capacity Advocacy (IMCA) Service - 2011/2012*, Department of Health, February 2013, page 6:

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/158009/Independent-Mental-Capacity-Service-_-fifth-annual-report.pdf.

social care sector”.²⁶⁴ Evidence we received supported that conclusion, although the British Institute of Learning Disabilities pointed out that a “more serious and troubling variation”²⁶⁵ was to be found between the social care and health care settings. The referrals for serious medical treatment were described as “worryingly low” leading to doubts about whether “medical professionals are actually complying with their legal duties”.²⁶⁶ The Derbyshire DoLS team agreed that “within hospitals, there is still greater variation in IMCA involvement”, when compared to social care.²⁶⁷ Brighton and Hove City Council suggested that this was due to different views of what constituted ‘serious medical treatment’, and that this “may result in IMCAs not being instructed as the legislation intends”.²⁶⁸

167. Despite the positive comments on IMCAs in general, there were reports of “much inconsistency across the country”.²⁶⁹ Some of this was attributed to a continuing confusion about the role, with the College of Social Work stating that “sometimes the IMCAs themselves are not always completely clear about what the different potential roles defined in the MCA entails”.²⁷⁰ Professor Fennell and Dr Series argued that it was far from clear in the legislation when an IMCA should challenge decision-making. They were concerned in particular by the suggestion that IMCAs would challenge decisions only when they judged them not to be in P’s best interests: “The right to obtain access to a court to air disputes under the MCA should not rest on the IMCA’s judgment call as to best interests, but the person’s own opposition to some measure which interferes with his ECHR rights and which is premised upon his ‘incapacity’”.²⁷¹ Irwin Mitchell LLP and others agreed that the primary focus of IMCAs should be “on promoting the individual’s views and wishes, not acting as a pseudo-independent best interests assessor”.²⁷² There was also a lack of clarity about whether or not an IMCA was able to act as a litigation friend, with some witnesses arguing that they should.²⁷³ Recent case law suggested it was possible in principle,²⁷⁴ but this did not appear to be widely known.
168. IMCAs were said to vary in their skills and knowledge and Sussex Partnership NHS Foundation Trust told us that this had an impact on how effectively they advocated on behalf of their clients.²⁷⁵ Beverley Dawkins of Mencap called for greater investment in training of IMCAs whose clients had

²⁶⁴ *Ibid.*

²⁶⁵ British Institute of Learning Disabilities.

²⁶⁶ *Ibid.*

²⁶⁷ Derbyshire DOLS team.

²⁶⁸ Brighton and Hove City Council.

²⁶⁹ Victoria Butler-Cole, Neil Allen, Andrew Bowmer, Julie Cornes, Charlotte Haworth Hird, Laura Hobey-Hamsher, Laura Jolley, John McKendrick, Alex Ruck Keene, Polly Sweeney, Rachel Turner and Paula Scully.

²⁷⁰ The College of Social Work.

²⁷¹ Professor Phil Fennel and Dr Lucy Series.

²⁷² Irwin Mitchell LLP; Victoria Butler-Cole, Neil Allen, Andrew Bowmer, Julie Cornes, Charlotte Haworth Hird, Laura Hobey-Hamsher, Laura Jolley, John McKendrick, Alex Ruck Keene, Polly Sweeney, Rachel Turner and Paula Scully.

²⁷³ Bristol Mind IMCA Service; Age UK Cheshire Advocacy; Doncaster Safeguarding Adults Partnership Board.

²⁷⁴ *AB v LCC (A Local Authority)* [2011] EWHC 3151 (COP).

²⁷⁵ Sussex Partnership NHS Foundation.

non-verbal communication, were in complex medical situations or who had challenging behaviour.²⁷⁶ Headway suggested that the specific impact of acquired brain injury on capacity required an IMCA with an understanding of those issues in order to advocate effectively on the client's behalf.²⁷⁷ The Standing Commission on Carers supported the call for IMCAs with expertise in specific areas.²⁷⁸

169. Regulations made under the Mental Capacity Act²⁷⁹ give local authorities powers to determine the training and qualifications required of IMCAs. The Code of Practice stipulates that all IMCAs “must have [attended] IMCA training,”²⁸⁰ but we note that the Code does not have the force of law.²⁸¹ According to the Social Care Institute for Excellence, IMCA training was originally a four day course.²⁸² Since 2009 national qualifications in independent advocacy have been available through a range of providers, with the support of the Department of Health. However, these are general advocacy qualifications, and the two units dealing specifically with the role of IMCAs are optional. Following the introduction of the advocacy qualification, it was expected that all IMCAs would complete the optional unit about the role of the IMCA, and where necessary also the unit concerning the role of an IMCA in relation to the Deprivation of Liberty Safeguards.²⁸³ A quality performance mark for independent advocacy was launched in 2008, but it was suggested that it needed updating.²⁸⁴
170. POHWER, an IMCA provider, argued for a national qualification or performance mark for IMCAs, rather than relying on standards set by contractual agreements: “This is a vital professional role within the MCA and should be treated as such in terms of accountability, performance checks [and] continual professional development”.²⁸⁵ Several witnesses called for the professionalisation of the role using either a mandatory professional qualification for IMCAs, or a quality performance mark against which there could be closer performance monitoring.²⁸⁶ Camden Adults Safeguarding Partnership Board wanted “national standards set for the IMCA role which are transparent and allow a pathway of recourse to address any issues arising”.²⁸⁷ They also argued for the IMCA role to be regulated by a central body, and that the absence of such regulation had resulted in regional variation in quality.²⁸⁸ Browne Jacobson LLP wanted to see a review of

²⁷⁶ Q 83.

²⁷⁷ Headway.

²⁷⁸ Standing Commission on Carers.

²⁷⁹ Mental Capacity Act 2005 (Independent Mental Capacity Advocates) (General) Regulations 2006.

²⁸⁰ Mental Capacity Act 2005 Code of Practice (2007), para. 10.18, p184.

²⁸¹ Certain categories of people have a legal duty to have regard to the code when working with or caring for adults who may lack capacity to make decisions for themselves, but they are not bound by the Code as they are by law.

²⁸² Commissioning and monitoring of Independent Mental Capacity Advocate (IMCA) services: The training and qualification of IMCAs: <http://www.scie.org.uk/publications/guides/guide31/issues/training.asp>.

²⁸³ *Ibid.*

²⁸⁴ Q 116.

²⁸⁵ POHWER.

²⁸⁶ Browne Jacobson LLP; Kate Beynon PSW/ BIA/ AMHP (Safeguarding Adults Team, Northamptonshire County Council); Camden Safeguarding Adults Partnership Board; Housing and Social Care Services, London Borough of Camden.

²⁸⁷ Camden Adults Safeguarding Partnership Board.

²⁸⁸ *Ibid.*

IMCA training, which they felt “has often been focussed on the MCA rather than the IMCA role specifically, and for which there is little quality assurance or accountability”.²⁸⁹

171. We also heard concern about the ability of IMCAs effectively to challenge decision-making by local authorities when those same authorities commissioned and paid for their services. The British Institute of Learning Disabilities said there was evidence that willingness to challenge was “not robust enough in some areas”.²⁹⁰ We were told that in some instances IMCAs who had challenged social workers had had official complaints made against them along with an instruction “to back off”.²⁹¹ Several witnesses argued that such conflicts of interest were inherent in the structure of commissioning of IMCA services,²⁹² though not everyone agreed. Mr Neary’s experience of the IMCA appointed to represent his son Steven was that she was “completely independent”, and felt under no compulsion to agree with the local authority’s view.²⁹³ Ms Oi Mei Li, Director of the National Family Carer Network, cited research by The Foundation for People with Learning Disabilities which found that when IMCAs were used there were more challenges “because they understand the processes and know what should be happening and when things are not being followed through”.²⁹⁴
172. Representatives from ADASS reported positive working relationships with IMCA service providers in their areas, and did not perceive a conflict of interests for IMCAs when challenging local authorities: “you would expect healthy challenge and healthy feedback on the way that you are operating ... It is part of the quality control of your department and your directorate.”²⁹⁵ Parallels were drawn with independent chairs for Safeguarding Boards. “You would not want somebody to say it is all okay ... there are always issues that need resolving”.²⁹⁶
173. Many witnesses called for the role of IMCAs to be extended, allowing them to be made available in a wider range of circumstances. BASW agreed that local authorities should have greater discretion about when to make a referral, and that it would be especially helpful in cases of dispute concerning a best interests decision.²⁹⁷ ADASS agreed.²⁹⁸ Others argued for an automatic referral where there was an application under the Deprivation of Liberty Safeguards, regardless of whether the person was befriended or not, and automatic referral where there were allegations of abuse or neglect.²⁹⁹ Other suggestions included an extension of remit to include all persons receiving a care assessment or plan under the Care Bill, or any important decisions, whether controversial or not.³⁰⁰

²⁸⁹ Browne Jacobson LLP.

²⁹⁰ British Institute of Learning Disabilities.

²⁹¹ Q 264.

²⁹² Irwin Mitchell LLP; Together for Mental Wellbeing; The Law Society; 3 Counties IMCA Service.

²⁹³ Q 264.

²⁹⁴ Q 136.

²⁹⁵ Q 183.

²⁹⁶ Q 183.

²⁹⁷ British Association of Social Workers.

²⁹⁸ Association of Directors of Adult Social Services (ADASS).

²⁹⁹ The Law Society; VoiceAbility; Advocacy Support Cymru.

³⁰⁰ VoiceAbility; Joanna Burton.

174. The 3 Counties IMCA Service questioned whether the IMCA system was “flawed as a safeguard” because it depended on referral by the decision-makers.³⁰¹ Mr Neary argued that anyone subject to a Deprivation of Liberty authorisation or their family should be able to approach an IMCA service directly, rather than relying on the local authority for a referral. In his son’s case the referral was delayed by over six months. The judge found that if an IMCA had been appointed sooner “Steven would have been home within weeks”.³⁰²
175. **The role of the IMCAs has been widely praised and much of the evidence calls for their role to be extended. We believe that extending the range of circumstances in which IMCAs are appointed, and involving them earlier in the decision-making process, would be beneficial.**
176. **We recommend that local authorities use their discretionary powers to appoint IMCAs more widely than is currently the case. To support this, we recommend the Government issue guidance to local authorities and health service commissioners about the benefits of wider and earlier use of IMCA services. We believe the costs of greater IMCA involvement should be balanced against the resources required in lengthy disputes or ultimately in litigation.**
177. **Given the importance of the role of IMCAs in the lives of vulnerable adults we believe that the role requires further professionalisation to ensure consistency of service. This should be achieved through national standards and mandatory training in the Mental Capacity Act and the role of the IMCA within that. We recommend that responsibility for such standards and training be undertaken by the independent oversight body which we recommend in chapter 4, enabling peer support and consistency between IMCA services.**
178. **We recommend that the Government consider the establishment of a form of self-referral for IMCA services to prevent the damaging delay that occurred in the case of Mr Steven Neary.**

Lasting Powers of Attorney

179. Evidence on the use of Lasting Powers of Attorney (LPAs) suggested they were underused and not widely known. Age UK said awareness of LPAs among the general population was low, and that access to good quality information was not always readily available.³⁰³ Not many people were aware of the two types of LPA, covering property and financial affairs on the one hand, and health and wellbeing on the other.³⁰⁴ Health and Welfare LPAs made up the minority of registered applications (20%) and there were calls for awareness of this type of LPA in particular to be raised.³⁰⁵ Age UK also identified a general reluctance to engage with the subject—people tended to put off worst-case planning.³⁰⁶ This was borne out by the meeting of the

³⁰¹ 3 Counties IMCA Service.

³⁰² Q 264.

³⁰³ Age UK.

³⁰⁴ *Ibid.*

³⁰⁵ British Association of Social Workers; London Borough of Bromley; Bracknell Forest Council.

³⁰⁶ Age UK.

Forget-Me-Nots, a peer support and advocacy group for people with dementia, which two members of the Committee attended. There was a desire to live for the day: “we don’t want to discuss this all the time”.³⁰⁷ The same was true of other family members: “It’s not just us who put it off, it becomes a taboo subject—family members don’t want to talk about it either”.³⁰⁸

180. Alzheimer’s Society said families and carers acting as deputies or attorneys found the Act confusing and lacked support in dealing with it, reporting a correspondingly high level of calls to their helpline regarding LPAs (1,356 queries between April 2012 and March 2013).³⁰⁹ They agreed with Age UK that take-up was low, in part due to low levels of awareness, but also in part because many people with dementia were not diagnosed or only diagnosed too late. As a result “fewer people with dementia have powers of attorney in place than could benefit from them”.³¹⁰
181. The Public Guardian, Mr Alan Eccles, said that he was “never satisfied with the numbers that are being taken up”.³¹¹ However, he referred to the growth rate as “phenomenal”: 49,000 LPAs were registered in 2008/09; that figure had jumped to 228,744 in 2012/13, and Mr Eccles believed the office to be on target to process 300,000 registrations in the current year. Those figures had been reached without any demonstrable effort to raise awareness of LPAs and the potential benefits of registration. However, Office of the Public Guardian had recently commissioned opinion research to gauge awareness levels, and was determined to tackle the potential barriers to take-up.³¹²
182. Witnesses expressed concern regarding the complexity of the forms and cost of registering an LPA. The paperwork was considered onerous and the assistance of a solicitor was often sought; this added to the burden of costs.³¹³ Mr Eccles told us that the Office of the Public Guardian was consulting on simplifying some of its forms, “to make the form shorter, and also to try to make some of the language in the forms more accessible to lay people who are making the applications for themselves”.³¹⁴ Mr Eccles informed us that the cost of registration had been reduced from £130 to £110, from 1 October 2013.³¹⁵
183. We were concerned to receive evidence that the powers granted by LPAs were often not recognised or understood. The Law Society reported that understanding of LPAs in the banking sector was generally very poor.³¹⁶ Age UK suggested that financial institutions tended to have the right procedures in place but that individual staff were not always aware of them. They called for training of all customer-facing staff to ensure good knowledge of the Act and the relevant procedures operated by their institutions.³¹⁷ Age UK had

³⁰⁷ Forget-Me-Nots.

³⁰⁸ *Ibid.*

³⁰⁹ Alzheimer’s Society.

³¹⁰ *Ibid.*

³¹¹ Q 284.

³¹² *Ibid.*

³¹³ Bracknell Forest Council.

³¹⁴ Q 281.

³¹⁵ Q 287.

³¹⁶ The Law Society.

³¹⁷ Age UK.

been involved in new guidance issued by the British Bankers Association (BBA) and the Building Societies Association (BSA) in April 2013 which they hoped would improve performance.³¹⁸ Alzheimer's Society also reported that they were working with banks and utility companies, among others, to raise awareness and improve systems.³¹⁹ The Office of the Public Guardian had also undertaken work with the BBA and the BSA "to make sure that they have awareness of lasting powers of attorney and deputyship orders, and what they should do".³²⁰ Good experiences were rare but made a big impact; one member of the Forget-Me-Nots, the dementia support group whom two Committee members met, told us "We have a great relationship with the bank and they help us a lot, we always see the same person".³²¹ Difficulties in accessing banking services are likely to increase for people who may lack capacity due to the growing complexity of financial transactions, such as the requirement for passwords and pin codes, which are necessary to prevent fraud and money laundering.

184. Access to information about LPAs that had been registered was seen as unsatisfactory. The Social Care Institute for Excellence (SCIE) said health and social care providers did not routinely ask whether an LPA had been made, or what it contained.³²² The Sheffield Safeguarding Adults Board said that LPAs were not necessarily recorded in hospital medical records, leaving staff in the dark about whom they needed to consult.³²³ The London MCA/DoLS network said that staff rarely felt confident to conduct appropriate checks on family members who claimed to be attorneys or deputies; they were unlikely to contact the Office of the Public Guardian for clarification as the process was time-consuming.³²⁴ This problem was considered particularly acute in emergency situations.³²⁵ Even in cases where the existence of an LPA was known about, evidence suggested that there was little knowledge in health settings of the powers exercised under a health and welfare LPA.³²⁶ We understand that the consultation by the Office of the Public Guardian entitled 'Digital by default', which closed in November 2013, included proposals for making its register available for searching; we are not yet aware of the outcome of the consultation.
185. Professor Jenny Kitzinger, who acted as a Court-appointed Welfare Deputy for her sister who was in a vegetative state, reported that "clinicians simply ignored the court order"; and on one occasion "new medical treatment was initiated without the necessary consent".³²⁷ She found little support from the Court when alerting them to the non-compliance, and without sanctions, she felt she had no way of making the clinicians take the order seriously. She suggested that the Court should provide some form of back-up to health and welfare Deputies and Attorneys who allege non-compliance, such as a letter

³¹⁸ *Ibid.*

³¹⁹ Alzheimer's Society.

³²⁰ Q 283.

³²¹ Forget-Me-Nots.

³²² Social Care Institute for Excellence (SCIE).

³²³ Sheffield Safeguarding Adults Board.

³²⁴ The London MCA/DOLS network.

³²⁵ Q 286.

³²⁶ West Sussex County Council.

³²⁷ Jenny Kitzinger.

from the Court reminding organisations of their obligations under the Act.³²⁸ The group of solicitors and barristers who jointly submitted evidence also reported incidents of statutory bodies not respecting the decisions of a Welfare Attorney.³²⁹

186. Low awareness of the requirements under the Act also appeared to be affecting the performance of attorneys and lay deputies. West Midlands Regional DoLS Leads Group reported that people were “rarely aware of the requirements of the Act” and needed support and guidance from social workers, resulting in increased workloads for social service departments.³³⁰ Professors Celia Kitinger and Jenny Kitinger reported misunderstandings about the scope of an LPA—for example, the holder of a finance LPA wrongly assuming they had decision-making power over matters of health and welfare as well.³³¹ Lancashire County Council found that LPA holders did not understand the need to follow the best interests checklist.³³² Senior Judge Denzil Lush told us that in his experience of financial abuse cases, attorneys and deputies showed a distinct lack of knowledge of the Code of Practice: “most attorneys and deputies are unaware that it exists ... almost none of them are interested”.³³³ Achieving better levels of awareness was considered crucial in ensuring compliance.³³⁴
187. There were concerns about the potential for abuse of property and financial affairs LPAs or deputyships. Senior Judge Denzil Lush told us he was “dismayed” at the extent of financial abuse that was emerging, particularly by close family members.³³⁵ The Association of Public Authority Deputies said that concerns had been raised “locally, regionally and nationally” about the capacity of the Office of the Public Guardian to respond to safeguarding alerts when financial abuse was suspected.³³⁶
188. Under section 58(1)(h) of the Act the Public Guardian has power to deal with complaints against deputies and attorneys. Lord McNally referred to this as “a rather passive power”.³³⁷ He added that the Government were considering whether the Public Guardian “could have the powers to be more proactive”.³³⁸ Mr Eccles told us that the main way in which his office was alerted to concerns regarding deputies and attorneys was through “some form of whistle-blowing”. His office had a whistle-blowing telephone line; and they also accepted referrals through the call centre, by letters or e-mail. Reports of concerns came from “all sorts of people” including family members, neighbours, social workers and banks. However, the main form of supervision was of deputies rather than attorneys, and that was through

³²⁸ *Ibid.*

³²⁹ Victoria Butler-Cole, Neil Allen, Andrew Bowmer, Julie Cornes, Charlotte Haworth Hird, Laura Hobey-Hamsher, Laura Jolley, John McKendrick, Alex Ruck Keene, Polly Sweeney, Rachel Turner and Paula Scully.

³³⁰ West Midlands Regional Dols Leads Group.

³³¹ Professor Celia Kitinger (University of York) and Professor Jenny Kitinger (Cardiff University).

³³² Lancashire County Council.

³³³ Senior Judge Denzil Lush.

³³⁴ Adrian Watts.

³³⁵ Senior Judge Denzil Lush.

³³⁶ Association of Public Authority Deputies.

³³⁷ Q 317.

³³⁸ *Ibid.*

monitoring of annual reports. Any discrepancies or delays were followed up and investigated. He hoped that the new back office management system and digital tools would make this supervisory function “as robust as possible”.³³⁹ There were currently 48,000 deputies and 880,000 LPAs registered; in the last financial year the Office of the Public Guardian investigated 718 cases. Mr Eccles suggested that those figures were reason to believe that “the vast majority of LPAs are working well, and that deputyship orders are working as the court intended them to work”.³⁴⁰

189. Solicitors for the Elderly thought it was likely that in making it easier to create an LPA, more incidents of financial abuse would follow. They cautioned against delivering ease and accessibility “at the expense of care and protection”.³⁴¹ We raised these concerns with Mr Eccles in light of the consultation about fully digitising the LPA application process. We were told that maintaining appropriate safeguards in the process was a key part of the consultation: “our commitment is that it will be as secure, if not more secure, by doing it online”.³⁴²
190. A small number of anomalies concerning the implementation of Lasting Powers of Attorney were drawn to our attention. One concerns the possibility of nominating successive attorneys. Mr and Mrs Boff described the attempt by Mrs Boff to appoint her husband as donee and to nominate their two children and a niece to act as successive replacement attorneys in an individual capacity.³⁴³ The reason for not nominating her children and niece to act jointly and severally, permissible under the Act, was Mrs Boff’s personal experience of acting as attorney for her own mother. Being appointed to act jointly and severally with her siblings had contributed to significant difficulty in managing her mother’s affairs and had convinced Mrs Boff to make different arrangements for her own LPA. The Court of Protection ruled that under section 10(8)(b) of the Act “a replacement attorney can only replace an original attorney and cannot replace a replacement attorney”.³⁴⁴ We were also told by a group of solicitors and barristers that it was not clear whether the entirety of schedule 3 of the Act was in force, and they sought clarification in particular of “what formal requirements must be complied with in order for a ‘foreign’ power of attorney to be effective in England and Wales”.³⁴⁵ This was particularly important in light of uncertainty over the status of Scottish powers of attorney in England.³⁴⁶
191. **As with other aspects of the Mental Capacity Act, low levels of awareness have affected implementation of the provisions relating to Lasting Powers of Attorney. Awareness needs to be raised among the**

³³⁹ Q 290.

³⁴⁰ *Ibid.*

³⁴¹ Solicitors for the Elderly.

³⁴² Q 287.

³⁴³ Mr and Mrs Boff.

³⁴⁴ *The Public Guardian v Ruth Minna Boff & James Charles Boff*, COP 12338771 (a judgement of the Senior Judge given on 16 August 2013):

<http://www.justice.gov.uk/downloads/protecting-the-vulnerable/mca/re-boff-judgment.pdf>.

³⁴⁵ Victoria Butler-Cole, Neil Allen, Andrew Bowmer, Julie Cornes, Charlotte Haworth Hird, Laura Hobe-Hamsher, Laura Jolley, John McKendrick, Alex Ruck Keene, Polly Sweeney, Rachel Turner and Paula Scully.

³⁴⁶ *Ibid.*

general public of the benefits of Lasting Powers of Attorney in order to encourage greater take-up, especially for Health and Welfare matters. We support the initiatives of the Public Guardian to improve take-up by simplifying the forms and reducing the cost of registration, as well as identifying other barriers to take-up.

192. **We recommend that the Government, working with the independent oversight body recommended in chapter 4, and the Office of the Public Guardian:**

- **address the poor levels of understanding of LPAs among professional groups, especially in the health and social care sector, paying specific attention to the status of Lasting Powers of Attorney in decision-making;**
- **consider how best to ensure that information concerning registered Lasting Powers of Attorney can be shared between public bodies, and where appropriate with private sector bodies such as banks and utilities;**
- **issue guidance to local authorities that their new responsibilities for provision of information in relation to care contained in the Care Bill should include information on Lasting Powers of Attorney;**
- **consider how attorneys and deputies faced with non-compliance by public bodies or private companies can be supported in the absence of specific sanctions;**
- **review the apparent anomalies in the current arrangements with regard to successive replacement attorneys, and the status in England of Scottish Powers of Attorney.**

Advance decisions to refuse treatment (ADRTs)

193. Officials told us that no data were collected concerning the making of advance decisions to refuse treatment,³⁴⁷ but in written evidence the Government assured us that it believed that “many more people know that they can refuse treatment and make choices about their end of life”.³⁴⁸ Nonetheless, evidence suggested that public awareness of advance decisions is low. Compassion in Dying cited research showing that only 3% of the public have made an advance decision, even though 82% have “clear views about their end-of-life care preferences”.³⁴⁹ It was also suggested by a number of witnesses that the introduction of welfare LPAs had led to a corresponding decrease in advance decisions,³⁵⁰ since having an attorney provided the prospect of advocacy and meaningful engagement with local authorities and other public bodies on behalf of the person concerned.³⁵¹

194. Browne Jacobson LLP described the effective use of advance decisions as a “comparative rarity”; more support was needed to ensure that they were

³⁴⁷ Q 16.

³⁴⁸ Ministry of Justice and Department of Health, supplementary.

³⁴⁹ Compassion in Dying.

³⁵⁰ Senior Judge Denzil Lush.

³⁵¹ Society of Trust and Estate Practitioners; Solicitors for the Elderly.

- valid and applied.³⁵² The North East London NHS Trust explained that it had a policy on advance decisions, including a standard format for drawing them up and guidance to staff on how to assist patients. Despite this, use of advance decisions was low, even among patients with chronic conditions. When advance decisions had been made, the standard was “poor and would be challenged if it was ever to be put into use”.³⁵³
195. Concern was expressed about the levels of awareness among professionals of the role and status of advance decisions. Steven Richards, of Edge Consultancy, told us that he feared “that many health staff don’t understand the rules and procedures for Advance Decisions in terms of recognising them and their authority or enabling patients to make them”.³⁵⁴ Serjeants’ Inn Chambers concurred, mentioning specifically that there was “no widely available and approved standard form for an Advance Decision with the result that on the rare occasions when doctors are presented with one, the text will be unfamiliar and they will be anxious about providing or withholding further treatment”.³⁵⁵ The Society of Trust and Estate Practitioners agreed that “knowledge of [advance decisions] and their effect amongst health care professionals is still very patchy”.³⁵⁶ The Royal College of Nursing conceded that there was concern that many nurses were not clear about advance decisions.³⁵⁷
196. Nevertheless, we received evidence from a number of hospital trusts who had made significant local efforts to raise awareness, encourage take-up and ensure respect for advance decisions.³⁵⁸ In Barnsley a document for recording advance decisions had been designed following local consultation. Many such documents had since been completed and there was evidence from A&E departments and palliative care units that these were being “understood, respected and upheld”.³⁵⁹ In Warrington and Halton Hospitals NHS Foundation Trust a standard operating procedure had been introduced; all advance decisions were checked and verified in the governance department and once all criteria had been met “an Alert is placed via Meditech which then prints off on all current and future patient admission screens and documentation”.³⁶⁰
197. How information about advance decisions is used is of course crucial. Despite a few examples of local good practice the evidence suggested that there was no “systematic process for the recording, storage and retrieval of this information at the time when the person who made the [advance decision] lost capacity”.³⁶¹ Research by the Mental Health Team at the University of Nottingham found that almost half of those who had made

³⁵² Browne Jacobson LLP.

³⁵³ North East London NHS Trust.

³⁵⁴ Steven Richards (Edge Training & Consultancy).

³⁵⁵ Serjeants’ Inn.

³⁵⁶ Society of Trust and Estate Practitioners; also St Helen’s Council.

³⁵⁷ Royal College of Nursing.

³⁵⁸ South Essex Partnership University Hospital Trust; Michael Stanley (Barnsley MBC/PCT); Warrington and Halton Hospitals NHS Foundation Trust; North East London NHS Trust.

³⁵⁹ Michael Stanley (Barnsley MBC/PCT).

³⁶⁰ Warrington and Halton Hospitals NHS Foundation Trust.

³⁶¹ The Advanced Decision Evaluation (ADE) in Bipolar Disorder Study Team, Institute of Mental Health, University of Nottingham.

advance decisions had not shared this information with others.³⁶² The team concluded they were “not confident that in emergency situations decision makers have an agreed pathway to determine the presence or lack of an Advance Decision”.³⁶³

198. The Law Society said that in its experience medical staff respected advance decisions as long as they were found to be valid and applicable; the difficulty usually arose in determining whether an advance decision was valid and applicable in relation to the treatment decision being made.³⁶⁴ They recommended greater engagement between patients and clinicians at the time of making the advance decision to avoid such difficulties.³⁶⁵
199. **Advance decisions to refuse treatment are an essential means of allowing individuals to determine their care in the event that they lose capacity. As with other aspects of the Act, the general public cannot benefit from this opportunity if they are not made aware of it. Similarly, advance decisions that are not recorded and shared with relevant public bodies are likely to be ineffective. Poor understanding among health and care staff needs to be addressed in order to promote the benefits of advance decisions to patients, as well as to ensure that they are followed when valid and applicable.**
200. **We recommend that the Government, working with the independent oversight body:**
- **urgently address the low level of awareness among the general public of advance decisions to refuse treatment;**
 - **promote better understanding among health care staff of advance decisions, in order to ensure that they are followed when valid and applicable;**
 - **promote early engagement between health care staff and patients about advance decisions to ensure that such decisions can meet the test of being valid and applicable when the need arises;**
 - **promote the inclusion of advance decisions in electronic medical records to meet the need for better recording, storage and communication of such decisions.**

³⁶² *Ibid.*

³⁶³ *Ibid.*

³⁶⁴ The Law Society.

³⁶⁵ *Ibid.*

CHAPTER 6: THE COURT OF PROTECTION

201. The Court of Protection has authority to make decisions on behalf of a person who lacks capacity. The Act itself is silent on when applications should be made, but the Code of Practice to the Act explains that certain decisions, by virtue of their seriousness, must be taken by the Court unless a valid and applicable advance decision is in place. The Code further explains that applications to the Court are also to be made in respect of particularly difficult decisions, or disagreements that cannot be resolved in any other way, including a person challenging an assessment that they lack capacity, and where ongoing decisions may need to be made about personal welfare, property or financial matters. In the absence of an LPA, applications to the court are necessary for dealing with certain cash assets, or for selling a person's property or where the person has a level of income or capital that the court thinks a deputy needs to manage.³⁶⁶

Is the Court of Protection appropriate?

202. Many witnesses valued the expertise of the Court, and its judgments were supported by service user organisations and local authorities.³⁶⁷ Mencap described the judgements of the Court as “thoughtful and helpful”, particularly concerning capacity and consent to treatment, sexual relationships and deprivation of liberty.³⁶⁸ Kirsty Keywood was “heartened” by rulings which showed “great humanity and compassion for the people and families whom they are supporting”.³⁶⁹ Lorraine Currie of Shropshire County Council referred to a “fantastic body of expertise” among the judges.³⁷⁰
203. Nevertheless many considered the Court to be remote, inaccessible and not well understood.³⁷¹ Some highlighted problems in gaining support to access the Court, with limitations on support available through legal aid³⁷² and the Official Solicitor,³⁷³ the limited ability of IMCAs to act as litigation friends,³⁷⁴ and concerns regarding the denial of litigation capacity.³⁷⁵ Some witnesses said it was unclear who should initiate proceedings in the Court of Protection.³⁷⁶ A number of legal professionals said that the Court of

³⁶⁶ MCA Code of Practice (2007), *Op. Cit.* para 8.35.

³⁶⁷ Mencap; Social Care Institute for Excellence.

³⁶⁸ Mencap.

³⁶⁹ Q 42.

³⁷⁰ Q 184.

³⁷¹ Social Care Institute for Excellence; South West IMCA Group; Mental Health Alliance.

³⁷² Official Solicitor to the Senior Courts; Rescare (The Society for Children and Adults with Learning Disabilities and their Families); Age UK; Royal Hospital for Neuro-disability; Victoria Butler-Cole, Neil Allen, Andrew Bowmer, Julie Cornes, Charlotte Haworth Hird, Laura Hobey-Hamsher, Laura Jolley, John McKendrick, Alex Ruck Keene, Polly Sweeney, Rachel Turner and Paula Scully.

³⁷³ Solicitors for the Elderly; Empowerment Matters CIC; Irwin Mitchell LLP.

³⁷⁴ VoiceAbility.

³⁷⁵ Professor Phil Fennell and Dr Lucy Series.

³⁷⁶ Housing and Social Care Services, London Borough of Camden.

Protection rules required updating in light of experience, citing unimplemented proposals dating back to 2010.³⁷⁷

204. A number of witnesses raised the cost of access to the Court, particularly in relation to cases concerning property and financial affairs, where the costs were usually met by P, even when they did not initiate the litigation.³⁷⁸ Some argued for lower court alternatives, such as a tribunal service or mediation. Moira Fraser, of the Carers Trust, reported that “our services tell us that they feel it is a sledgehammer approach for comparatively small amounts of money ... someone told me that they needed access to less than £5,000 for essential repairs to their mother’s house; they had to go to the Court of Protection ... and it took forever”.³⁷⁹ We consider these issues in more detail below.

Delays

205. The workload of the Court of Protection has increased year on year since it was established, with 24,586 applications received in 2012, compared to 19,528 in 2009.³⁸⁰ Responding to concerns about access and delays, District Judge Elizabeth Batten told us that:

“we acknowledge that we have had real problems. We would just like to communicate the fact that our workload has increased by 25% since 2009. Over that time, our staffing has reduced from 118 people in London to 86, a reduction of 30%. We have also been through a process whereby more experienced staff have been replaced by less experienced staff”.³⁸¹

We raised the issue of resourcing with Lord McNally who replied that this was a fact of life: “we are constantly asking public servants to do more for less”.³⁸²

206. Mr Justice Charles argued that, despite this reduction in resources and increasing workload, the Court had maintained or improved performance against its key performance indicators.³⁸³ These consisted of a target of replying to initial applications within 20 working days in 95% of cases, met in 99% of cases in 2012/13; a target of giving directions where there is no oral hearing within 16 weeks in 75% of cases, met in 72% of cases in 2012/13; and a further target of giving directions where there is no oral hearing within 20 weeks in 98% of cases, achieved in 79% of cases in 2012/13.³⁸⁴ However, based on the figures provided by the Court of Protection, performance

³⁷⁷ Victoria Butler-Cole, Neil Allen, Andrew Bowmer, Julie Cornes, Charlotte Haworth Hird, Laura Hobe-Hamsher, Laura Jolley, John McKendrick, Alex Ruck Keene, Polly Sweeney, Rachel Turner and Paula Scully. An *ad hoc* Rules Committee of the Court of Protection recommended a series of changes to update the Rules in 2010, only one of which has been implemented. In addition, Alex Ruck Keene, a barrister and former member of the *ad hoc* Rules Committee, wrote to us arguing for further amendments to the rules to reflect the changes that have since taken place in the Courts system more widely, including the move of the Court of Protection into the Family Division.

³⁷⁸ David Rees; Royal Hospital for Neuro-Disability.; Q 248 (Julia Lomas, Irwin Mitchell LLP).

³⁷⁹ Q 138.

³⁸⁰ Mr Justice Charles.

³⁸¹ Q 305.

³⁸² Q 330.

³⁸³ Mr Justice Charles.

³⁸⁴ *Ibid.*

against the two targets for giving directions had deteriorated since 2009/10, when 78% of cases requiring no oral hearing received directions within 16 weeks, and 85% of such cases received directions within 20 weeks.³⁸⁵ Furthermore, the target of replying to initial applications within 20 working days of receipt appears generous, and we have some sympathy, therefore, with concerns raised about delays.

207. Efforts to increase the accessibility and responsiveness of the Court were made in the proposals of the *ad hoc* Rules Committee of the Court of Protection in 2010³⁸⁶ and in the course of subsequent work on updating application forms. Only one recommendation of the *ad hoc* Rules Committee had been implemented so far; we were told that further implementation depended on support from the Ministry of Justice.³⁸⁷ Mr Justice Charles explained that there were “long running problems relating to the failure to make amendments to the Rules”.³⁸⁸ At present the rules made no distinction between non-contentious property and financial affairs applications which were processed without oral hearings, and the remaining case-load of contested applications in either property and financial affairs or health and welfare.³⁸⁹
208. However, the one recommendation that was adopted had resulted in the appointment of ‘authorised officers’, i.e. non-judicial staff, to complete the routine administration of non-controversial property and financial affairs matters. This change was designed to remove the backlog of cases, and had enabled the Court to handle routine property and financial affairs decisions, such as permission to buy a property, more quickly.³⁹⁰ Solicitors for the Elderly welcomed the change, which had speeded up the process, but they argued that it was still taking too long to deal with matters such as orders for house purchase or disputed Power of Attorney matters.³⁹¹ Julia Lomas from Irwin Mitchell LLP argued for the number of authorised officers to be increased “simply because they can cut through so many of the standard decisions that are needed on property and affairs”.³⁹² The Committee learned during its visit to the Court of Protection that there are four ‘authorised officers’. They admitted that their small number created a pinch point in the process. When necessary, support was called in from the pool of District Judges.³⁹³
209. **We note the considerable strain on the processing of applications to the Court of Protection, due to the increased volume of work and significant cuts in staffing. Despite the appointment of authorised officers to handle non-controversial property and financial affairs applications, there continues to be a bottleneck in the process. We are**

³⁸⁵ *Ibid.*

³⁸⁶ Report of the *ad hoc* Court of Protection Rules Committee, August 2010: <http://www.judiciary.gov.uk/Resources/JCO/Documents/Reports/committee-report-court-protection-29072010.pdf>.

³⁸⁷ Q 293. See also footnote 377.

³⁸⁸ Mr Justice Charles.

³⁸⁹ *Ibid.*

³⁹⁰ *Ibid.*

³⁹¹ Solicitors for the Elderly.

³⁹² Q 258.

³⁹³ Note of the Committee Visit to the Court of Protection. See appendix 10.

concerned that the means by which this bottleneck is currently eased is from the pool of District Judges. It is questionable whether a system which relies on District Judges deputising for non-judicial staff is cost-effective or proportionate.

210. **We recommend the Government consider increasing the staff complement of authorised officers, following consultation with the Court of Protection, to achieve a significant reduction in the time taken to deal with non-contentious property and financial affairs cases.**
211. **We also recommend that the Government consider as a matter of urgency the updating of the Rules of the Court, as recommended by the *ad hoc* Rules Committee and, as necessary, in light of subsequent changes.**

Transparency

212. While much publicity is given to the decisions of the Court concerning medical or welfare matters, the vast majority of the case load is made up of non-contentious property and financial affairs cases decided without formal Court hearings. These constitute around 90% of the work.³⁹⁴ Mr Justice Charles, Vice-President of the Court of Protection, argued that real care needed to be taken to ensure that “the tail does not wag the dog”—the tail being the high profile welfare cases, while “90% are the dog”.³⁹⁵
213. Media reporting of the Court of Protection tends to focus on the fact that its proceedings are held in private, and not all judgments are published, leading some to refer to it as a “secret court”.³⁹⁶ Such concerns were not widely raised in the evidence we received, though more open reporting of Court of Protection cases was seen as “important for the transparency of justice, and vital to counter some of the disparaging perceptions and media coverage of the Court as some secret tribunal”.³⁹⁷
214. We put these issues to the judiciary and to the Government. Mr Justice Charles and Lord McNally supported greater openness in the interests of transparent justice, while acknowledging the need to protect the privacy of individuals involved in cases.³⁹⁸ Lord McNally argued that “transparency is the best disinfectant against abuse by people in power.”³⁹⁹ Mr Justice Charles pointed to another benefit:

“The other major advantage of having greater openness would be that it would improve the performance of all involved in the court process. I do not exclude the judges from that, but I think it would definitely improve the identification of issues and prevent quite a lot of family litigants making points that they would simply be embarrassed to make if other people were hearing them, if truth be known”.⁴⁰⁰

³⁹⁴ Mr Justice Charles.

³⁹⁵ Q 292.

³⁹⁶ John Hemming MP (Chairman – Justice for Families); Mira Makar MA FCA.

³⁹⁷ Browne Jacobson LLP.

³⁹⁸ Mr Justice Charles; Q 329.

³⁹⁹ Q 329.

⁴⁰⁰ Q 309.

215. Since taking evidence on these matters, Sir James Munby, President of the Court of Protection, has issued new practice guidance on the publication of judgments in the Court of Protection, with the effect that more judgments will be routinely made available for publication. In publishing the guidance, Sir James Munby explained that:

“there is a need for greater transparency in order to improve public understanding of the court process and confidence in the court system. At present too few judgments are made available to the public, which has a legitimate interest in being able to read what is being done by the judges in its name”.⁴⁰¹

216. **We believe that the reputation of the Court will improve with greater transparency. We therefore welcome the decision by the President of the Court of Protection to make more judgments available to the public.**

217. Another way to improve the accessibility of the Court, and reduce its perceived remoteness, is to improve the information provided online. The Court has specific audiences to communicate with, including not only professionals, but also carers, litigation friends and those who may lack capacity or require support to access information to enable decision-making. The staff of the Court, whom we met on our visit, were concerned by their lack of ownership of the web content provided via www.gov.uk.⁴⁰² Their concern was borne out by a witness who argued that the Court had become less accessible when “the Government decided that they should lose their own websites”.⁴⁰³ Mr Justice Charles said that a dedicated website was not necessary, but that having control over the information relating to the Court was.⁴⁰⁴ District Judge Elizabeth Batten explained that “not having control of that does limit our ability to put forward what we want to communicate to the public and to users about what we do”.⁴⁰⁵

218. **We are persuaded that the Court of Protection has a range of audiences requiring access to information for professional or personal reasons, and that the staff and judiciary of the Court are best placed to determine what that information should be.**

219. **We recommend that the Government consider enabling the Court to address the needs of its audiences either by giving it greater control of the information provided on www.gov.uk or by enabling the Court to have a dedicated website.**

A Mental Capacity Tribunal?

220. One proposal to make access to justice more readily available was for a lower-tier tribunal system, similar to that operated under the Mental Health Act, particularly in respect of the deprivation of liberty safeguards. West Sussex County Council told us that “the lack of a tribunal system means that

⁴⁰¹ Practice Guidance, *Transparency in the Court of Protection: Publication of Judgements*, Sir James Munby, 16 January 2014, paragraph 2:

<http://www.judiciary.gov.uk/Resources/ICO/Documents/Guidance/transparency-in-the-cop.pdf>.

⁴⁰² Note of Committee Visit to the Court of Protection. See appendix 10.

⁴⁰³ Peter Edwards (Director, Peter Edwards Law).

⁴⁰⁴ Q 304.

⁴⁰⁵ *Ibid.*

challenges are expensive, difficult and involve delays,⁴⁰⁶ and Professor Jones was one of many witnesses who argued that “serious consideration should be given to an alternative tribunal structure”.⁴⁰⁷

221. Support for such a system was not universal. Other ways of making the Court more accessible and less costly, such as removing the need for expert witnesses, increasing regional hearings and nominating local judges, were suggested in order to speed up the process.⁴⁰⁸ Alex Ruck Keene thought that a tribunal layer would not necessarily add anything, but that there was a need for “much more aggressive time limits on how quickly a case needs to be progressed through the system and how quickly the court would be expecting to see evidence being produced by people.” He felt that some of the evidence gathering work, such as obtaining expert witness reports, was necessary, but some was “perhaps slightly Rolls-Royce”.⁴⁰⁹ There were also questions about how a tribunal system would be funded and staffed, and whether it would deliver promised benefits.⁴¹⁰ Alex Rook of Irwin Mitchell LLP was unsure what a tribunal system would achieve “because decisions are already taken at district judge level that are fairly accessible. It is probably equivalent to a Mental Health Review Tribunal already”.⁴¹¹
222. Evidence from the judiciary suggested that access to justice would not necessarily improve with the establishment of tribunals. Since tribunals were usually composed of panels of three people, the feasibility of reconvening the tribunal, as was often required in cases brought to the Court of Protection, would depend on the availability of all three panel members and would inevitably impact on the time table. The alternative, for a case to be heard by a new tribunal with no previous experience of the case, would impede continuity of oversight.⁴¹² Concern was also expressed that while a tribunal system would have the benefit of being local “the balance goes against it in the context of the Mental Capacity Act”.⁴¹³ This was because the issues under the Act were often multifaceted, with the result that “Many best interests issues that come before the decision maker involve a wide range of fact-finding, which is something that tribunals do less of than courts”.⁴¹⁴
223. **While we have sympathy with concerns raised regarding access and delay, we believe that the replacement of the Court with a new tribunal system would risk the loss of expertise and potentially increase costs in the system. We therefore conclude that a new tribunal system would not be the best way to address these concerns.**

⁴⁰⁶ West Sussex County Council.

⁴⁰⁷ Q 25; Safeguarding Essex; Sheffield Safeguarding Adults Board; Shropshire Council; London Borough of Bromley; Derek Boothby AMHP/ BIA; British Association of Social Workers.

⁴⁰⁸ Q 184; Q 258.

⁴⁰⁹ Q 258.

⁴¹⁰ Q 184.

⁴¹¹ Q 250.

⁴¹² Q 302.

⁴¹³ *Ibid.*

⁴¹⁴ *Ibid.*

Mediation

224. An alternative proposal presented by some witnesses was for greater use of mediation before matters escalated to court.⁴¹⁵ This was mentioned particularly in relation to property and financial affairs cases where the cost of the litigation was met from P's estate. In the absence of a power to award costs against other parties, except in exceptional circumstances, there was very little incentive for the parties to reach agreement.⁴¹⁶ BASW argued that better mediation services would avoid "hasty" applications to the Court and could help to encourage consensus between parties involved in the care of an incapacitated adult.⁴¹⁷ Joanna Burton, a solicitor who advises a large local authority in England, emphasised the benefits of a less adversarial approach to resolve disputes in light of the ongoing relationships between parties: "Whatever the outcome of a dispute P, the [local authority] social workers and P's family are almost certainly going to have to work together when it is resolved and/or the proceedings are over and the less adversarial this process is the better for P".⁴¹⁸
225. While supporting mediation in principle, the judiciary questioned how it would be delivered. District Judge Batten explained that "Particularly in property and affairs cases, it can be that nobody in the family wants anything to do with the local authority" meaning that local authority provided mediation would be unsuitable.⁴¹⁹ The group of solicitors and barristers argued that the Legal Aid Agency should be more willing to fund representation at mediation.⁴²⁰
226. There was support from Ministers for mediation. Mr Lamb told us that "anything that avoids the need to go to court seems to me to be on the whole a good thing".⁴²¹ Lord McNally said he was an "absolute enthusiast" for mediation, although it could not replace the role of the Court, which remained the "final arbiter".⁴²²
227. Despite this widespread support, the availability of mediation appeared to be limited in practice. Mind and Empowerment Matters suggested that this had led to an inappropriate tendency to expect IMCAs to fill this role,⁴²³ because "the Act promotes mediation when family disagree yet the only mediation that exists is often within a legal context and is costly".⁴²⁴
228. A number of witnesses discussed how such services would be resourced. On the one hand, it was argued that greater use of mediation would reduce the number of cases going through the formal court system, bringing about savings. Mr Lamb suggested that there was a "reasonable prospect" of the

⁴¹⁵ VoiceAbility; British Association of Social Work; Jenny Kitzinger; Adrian Watts; The Law Society.

⁴¹⁶ Note of the Committee Visit to the Court of Protection. See appendix 10.

⁴¹⁷ British Association of Social Work.

⁴¹⁸ Joanna Burton.

⁴¹⁹ Q 311.

⁴²⁰ Victoria Butler-Cole, Neil Allen, Andrew Bowmer, Julie Cornes, Charlotte Haworth Hird, Laura Hobey-Hamsher, Laura Jolley, John McKendrick, Alex Ruck Keene, Polly Sweeney, Rachel Turner and Paula Scully.

⁴²¹ Q 327.

⁴²² *Ibid.*

⁴²³ Mind; Empowerment Matters CIC.

⁴²⁴ Empowerment Matters CIC.

NHS and local authorities funding mediation from such savings.⁴²⁵ On the other hand, we were told by BASW that “mediation is not a cheap alternative. It has to be done correctly, professionally and competently, and it also requires a degree of independence”.⁴²⁶ Whereas in the past public authorities had set aside resources to develop such services, this was now difficult for them.⁴²⁷

229. We understand that the Office of the Public Guardian is to undertake a pilot study to “determine whether an in-house mediation service is a feasible option”.⁴²⁸ We were told that cases where mediation might be particularly useful were those involving disagreement between family members, “usually involving one or more attorneys ... or a Court appointed Deputy”⁴²⁹ and that cases selected for the pilot were likely to focus on property and financial affairs.⁴³⁰ However, we were disappointed to learn that the pilot will involve only 15-20 cases, and that mediation would take place via the telephone. Building relationships and establishing trust are vital in mediation. Moreover, mediation carried out under the Mental Capacity Act should conform to the framework for decision-making set out in the Act, including taking all practicable steps to help P to make the decision for themselves; and where this is not possible, following the best interests principle and process. We find it difficult to envisage how this can be done effectively without face to face communication, and we question how P can be appropriately involved and visible within the process without it.
230. **The Office of the Public Guardian appears to be well placed to provide a mediation service in cases of dispute involving holders of Lasting Powers of Attorney or Court appointed deputies. We are concerned, however, that their proposed pilot study will not provide robust data upon which to make a decision about the feasibility of such a service because of the small sample size and the decision to conduct mediation by telephone.**
231. **Mediation under the Mental Capacity Act should conform to the decision-making framework set out in the Act, and provision must be made to ensure that the views and wishes of P are adequately represented and central to the outcome. We recommend that the evaluation of the mediation pilot by the Office of the Public Guardian includes consideration of the extent to which the principles of the Act were reflected in the process.**
232. **We are persuaded that mediation would be beneficial in many more cases prior to initiating proceedings in the Court of Protection. We recommend that consideration be given to making mediation a pre-requisite for launching proceedings, especially in cases concerning property and financial affairs where the costs fall to P.**

⁴²⁵ Q 327.

⁴²⁶ Q 151.

⁴²⁷ *Ibid.*

⁴²⁸ Letter from Lord McNally, Minister of State for Justice, 10 December 2013. See appendix 7.

⁴²⁹ *Ibid.*

⁴³⁰ *Ibid.*

Access to the Court

233. We heard evidence of barriers to accessing the Court of Protection. Professor Fennell and Dr Series highlighted problems faced by individuals wanting to challenge an assessment that they lacked capacity or a decision said to be in their best interests. They argued that while there “are no explicit statutory or regulatory bars against people who ‘lack mental capacity’ making an application ... people who are said to lack capacity will face many practical difficulties in bringing proceedings”.⁴³¹ They suggested that these difficulties “dilute the right of access to a court under the MCA to a point where its protection is more likely to be ‘theoretical and illusory’ rather than ‘practical and effective’”.⁴³²
234. Alex Rook of Irwin Mitchell LLP argued that “there is a real lack of clarity” on the question of who should bring a case to court and called for clearer guidance from the Code of Practice on this.⁴³³ Mencap explained that the *Neary* case⁴³⁴ had made it clear “that the onus should be on the [Local Authority] to refer cases to the Court of Protection when there was disagreement about best interests” and had highlighted this case to families “to make them aware that they can ask for a case to be referred and that the onus should not be on them to actually refer it”.⁴³⁵ Nevertheless, Nicola Mackintosh reported that in her experience public authorities did not bring such cases: “what happens is that the statutory body just goes ahead and makes the decision, and leaves it ... to some other person, to bring the case before the court. Often that simply does not happen.”⁴³⁶ Irwin Mitchell LLP agreed that a local authority was unlikely to refer a case to the Court to question its own best interests decision, suggesting that the IMCA role to do so should be stronger.⁴³⁷
235. Professor Fennell and Dr Series raised a further concern about access to the Court in relation to “situations where professionals and family are in agreement as to a person’s capacity and best interests, but where the person themselves is not.”⁴³⁸ In such a situation the person was unlikely to have an independent mental capacity advocate, and the ruling in *Neary* appeared not to require the public authority to refer such a case to court. They argued that “surely, under the ECHR, a person’s rights to access justice to assert their capacity cannot hinge on something so arbitrary as whether or not their relations and professionals have fallen out?”⁴³⁹
236. **We are concerned that the responsibility of public authorities to initiate proceedings in cases of dispute is not widely known or adhered to. We also share the concerns of Professor Fennell and Dr Series regarding the ability of the person concerned to challenge decision-making when all others are in agreement.**

⁴³¹ Professor Phil Fennell and Dr Lucy Series.

⁴³² *Ibid.*

⁴³³ Q 256.

⁴³⁴ *London Borough of Hillingdon v Neary & Anor* [2011] EWHC 1377 (COP) §33.

⁴³⁵ Mencap.

⁴³⁶ Q 42.

⁴³⁷ Irwin Mitchell LLP.

⁴³⁸ Professor Phil Fennell and Dr Lucy Series.

⁴³⁹ *Ibid.*

237. **We recommend that the Government, and in future the independent oversight body, provide clearer guidance to public authorities regarding which disputes under the Act must be proactively referred to the Court by local authorities. This should include situations in which it is the person who is alleged to lack capacity who disagrees with the proposed course of action. Efforts must be made to disseminate this guidance to families and carers as well as to local authorities.**

Legal Aid

238. Restrictions in the availability of legal aid, and practical difficulties in accessing it, were a strong theme in concerns over access to the Court of Protection. Nicola Mackintosh and Sophy Miles, both expert legal practitioners in the area, explained that “due to the way in which the scope of legal aid has changed from ‘it’s available unless it is excluded’ to ‘unless a case falls within the list it will be out of scope’, it is likely that some cases which were previously within the scope of legal aid may now fall outside”.⁴⁴⁰
239. Non-means tested legal aid is available for appeals against a standard authorisation made by a local authority acting as supervisory body to deprive someone of their liberty, under schedule A1 of the Act.⁴⁴¹ However, some deprivations of liberty are authorised directly by the Court of Protection and these appear now to be ineligible for legal aid following recent changes under the Legal Aid, Sentencing and Punishing of Offenders Act 2012. Two types of cases falling into this category were drawn to our attention.
240. If an authorisation expires and is not renewed by the local authority while appeal proceedings are underway, the Court of Protection has in the past authorised the deprivation directly for the duration of proceedings. However, under the recent changes to legal aid, deprivations authorised by the Court are no longer eligible for non-means tested legal aid, potentially resulting in legal aid being withdrawn during proceedings and cases being discontinued.⁴⁴² This matter was also raised as a concern by the Official Solicitor.⁴⁴³
241. The second example concerned a deprivation of liberty in supported living accommodation. Only care homes and hospitals are subject to the standard authorisation procedure. However, deprivations in supported accommodation may be authorised directly by the Court. The Law Society said that as a result “for one group of detained persons legal aid is free; for another, because the court authorised the detention, it is not free and P may be prevented from accessing legal advice.” This was “an unjustifiable barrier to P’s rights under Article 5(4)” of the European Convention on Human Rights.⁴⁴⁴
242. Another source of concern was the fact that non-means tested legal aid is not available where an unauthorised deprivation of liberty is alleged. As Alex Rook of Irwin Mitchell LLP explained: “If you are saying, ‘My family

⁴⁴⁰ Nicola Mackintosh and Sophy Miles.

⁴⁴¹ The Civil Legal Aid (Financial Resources and Payment for Services) Regulations 2013, regulation 5 (g).

⁴⁴² Nicola Mackintosh and Sophy Miles.

⁴⁴³ The Official Solicitor to the Senior Courts.

⁴⁴⁴ The Law Society.

member ... is being deprived of their liberty’, and the public authority says, ‘No, they’re not’, you do not get non-means tested legal aid”.⁴⁴⁵ Mr Neary reported that he was frequently contacted by people in this situation.⁴⁴⁶ A personal submission, describing the story of a woman (WM) who had acted as a relevant person’s representative for her friend (MS) in order to challenge her deprivation of liberty, explained how legal aid was withdrawn after a Best Interests Assessment concluded that there was no such deprivation. As a result WM no longer retained the position as relevant person’s representative and the legal aid was lost. Without legal aid WM was not able to “continue a legal fight for her friend’s wellbeing”.⁴⁴⁷

243. The means testing of legal aid for all other areas falling under the Act, including for serious medical cases or cases affecting a person’s right to life, was also seen as problematic by many witnesses.⁴⁴⁸ The Official Solicitor, the ‘litigation friend of last resort’ for those who lack litigation capacity, told us that his office had traditionally funded litigation in medical cases from his own budget, subject to seeking to recover half the costs from the hospital.⁴⁴⁹ He had, nevertheless, refused representation outside these circumstances because of a lack of legal aid. This was because legal aid was available to those who lack litigation capacity in the same way as it is to any person in any normal form of litigation. He told us: “some of my staff spend a lot of their time trying to work out how to fund the representation of the person I have been asked to act as litigation friend for”.⁴⁵⁰ A group of solicitors and barristers reported that this had resulted in cases where no court proceedings could take place, because there was no-one willing or able to act as litigation friend, and they argued for the Official Solicitor’s office to “be resourced so that he is genuinely a litigation friend of last resort who can act regardless of P’s resources, as he does in medical treatment cases”.⁴⁵¹
244. A similar concern was reflected in the report of the Joint Committee on Human Rights (JCHR) in their consideration of proposals to introduce a residency test for legal aid eligibility, whereby an individual would be denied legal aid if they could not provide evidence of having resided in the UK for at least 12 months. The JCHR considered the effect of these proposals on those who lack the mental capacity to litigate. If denied legal aid on the ground of residency, such a person “would have no access to the court whatsoever,” because they would be prohibited from acting as litigant in person.⁴⁵² Sophy Miles and Nicola Mackintosh also raised concerns about the documentation required to satisfy the proposed residency test. They argued that:

“many people who lack capacity will not have passports, or other documentary evidence of lawful residence, and because their paperwork

⁴⁴⁵ Q 257.

⁴⁴⁶ Mark Neary.

⁴⁴⁷ MM.

⁴⁴⁸ Age UK Cheshire Advocacy; Irwin Mitchell LLP; Joanna Burton.

⁴⁴⁹ Q 274.

⁴⁵⁰ Q 275.

⁴⁵¹ Alex Ruck Keene, Neil Allen, Victoria Butler-Cole, Andrew Bowmer, Julie Cornes, Charlotte Hayworth Hird, Laura Hobey-Hamsher, Laura Jolley, John McKendrick, Polly Sweeney, Rachel Turner and Paula Scully.

⁴⁵² Joint Committee on Human Rights, *The Implications for access to justice of the Government’s proposals to reform legal aid* (7th Report of Session 2013-14, HL Paper 100 HC 766), paras 122 & 123: <http://www.publications.parliament.uk/pa/jt201314/jtselect/jtrights/100/10002.htm>.

is often being managed by others (who could be in a position of conflict) this is of significant concern because very vulnerable people at risk of abuse or neglect will be left without protection”.⁴⁵³

245. Advocacy Support Cymru argued that, even where legal aid was available, there were significant barriers to access.⁴⁵⁴ Changes to the way in which the means test is applied, it was suggested, have impacted particularly on those who may lack capacity.⁴⁵⁵ Evidence of income and capital, required in applications for legal aid, may be held by a family member rather than P, raising particular problems in the case of family disputes,⁴⁵⁶ delays in obtaining confirmation of benefits claims were also reported.⁴⁵⁷
246. Lord McNally explained that the policy intention behind the provision of legal aid in cases under the Act, was to “layer the application of legal aid in a way that gave absolute access when it was a question of liberty and then to phase it out with what we considered to be less essential issues”.⁴⁵⁸ As such, the creation of lasting powers of attorney or advance decisions to refuse treatment were not considered to be of “sufficient priority” to justify funding through legal aid.⁴⁵⁹ Means tested legal aid was available for Mental Capacity Act matters “that are within the scope of civil legal aid ... including cases involving medical treatment, welfare issues and other best-interest decisions”.⁴⁶⁰ This reflected the policy that “civil legal aid should be focused on the most financially vulnerable clients”.⁴⁶¹ Non-means tested legal aid would be available “where it was a matter of personal liberty”, as “such cases are regarded as a particularly strong example of state intervention involving the human rights of a vulnerable individual”.⁴⁶² We took this to mean all cases involving a deprivation of liberty, regardless of how it was authorised.
247. However, further information provided by the Ministry of Justice following the evidence session with Lord McNally appeared to narrow the application of “absolute access when it was a question of liberty”.⁴⁶³ We were told that changes contained in the Legal Aid, Sentencing and Punishment Offenders Act 2012 were intended “to put beyond doubt that means free funding was only to apply where an authorisation was in force and was the subject of a challenge under section 21A of the Mental Capacity Act 2005”.⁴⁶⁴ This specifically excludes deprivations authorised by the Court, or cases where a deprivation is alleged, but disputed.
248. **The Mental Capacity Act concerns some of the most vulnerable individuals in society, whom the law recognises may require support**

⁴⁵³ Nicola Mackintosh and Sophy Miles.

⁴⁵⁴ Advocacy Support Cymru.

⁴⁵⁵ Nicola Mackintosh and Sophy Miles; Victoria Butler-Cole, Neil Allen, Andrew Bowmer, Julie Cornes, Charlotte Haworth Hird, Laura Hobey-Hamsher, Laura Jolley, John McKendrick, Alex Ruck Keene, Polly Sweeney, Rachel Turner and Paula Scully.

⁴⁵⁶ Q 257.

⁴⁵⁷ Nicola Mackintosh and Sophy Miles.

⁴⁵⁸ Q 332.

⁴⁵⁹ *Ibid.*

⁴⁶⁰ *Ibid.*

⁴⁶¹ *Ibid.*

⁴⁶² *Ibid.*

⁴⁶³ *Ibid.*

⁴⁶⁴ Memorandum from Ministry of Justice, 12 February 2014. See appendix 8.

to make decisions. That such individuals will require support to access the legal system is indisputable.

- 249. We note the pressures on legal aid, but we are concerned by the inconsistent provision of non-means tested legal aid for cases concerning a deprivation of liberty, including those where there is a dispute over whether a deprivation is taking place. We cannot see a justification for such inconsistency and we recommend that the gap in protection that it creates be remedied as a matter of urgency.**
- 250. We are concerned by reports that those found to lack litigation capacity are prevented from bringing proceedings due to a lack of legal aid, and note the concerns raised in this regard by the Joint Committee on Human Rights. We are particularly concerned that individuals whom the Court of Protection has asked the Official Solicitor to represent are being refused representation on the grounds of ineligibility for legal aid.**
- 251. We recommend that the Government reconsider the provision of resources to the Official Solicitor, with a view to determining whether some cases merit the same unconditional support as is currently afforded to medical treatment decisions.**
- 252. We further recommend that the Government review the policy underlying the availability of legal aid for those who lack the mental capacity to litigate and therefore cannot represent themselves. For such people, denial of legal aid may result in having no access to Court. No-one who is found to lack the mental capacity to litigate should be denied access to Court solely because they do not have the means to pay for representation.**

CHAPTER 7: DEPRIVATION OF LIBERTY SAFEGUARDS

Background

253. The Deprivation of Liberty Safeguards (frequently known as DoLS) were not part of the original Mental Capacity Act in 2005. Introduced as amendments via the Mental Health Act 2007 in response to the findings of the European Court of Human Rights in the *Bournewood* case (see Box 7 below) and enacted in 2009, they are often seen as entirely separate from the rest of the Act. As Professor Jones explained: “although the DoLS legislation is part of the Mental Capacity Act, in practice they are two separate pieces of legislation. That is how they are regarded”.⁴⁶⁵

BOX 7

The Bournewood gap

The change in the law introducing the Deprivation of Liberty Safeguards was necessary following the decision of the European Court of Human Rights in *HL v United Kingdom* (2004),⁴⁶⁶ concerning the deprivation of liberty of an autistic man with a profound learning disability. HL had lived at Bournewood hospital for 32 years before being cared for by Mr and Mrs E. in their home under a resettlement scheme, where he lived for three years. In 1997 he was admitted back into Bournewood hospital following an incident in a day care centre, where he had become agitated, hitting himself on the head with his fists and banging his head against a wall. Clear instructions were given that if he attempted to leave the hospital, he should be sectioned under the Mental Health Act 1983, but he never made this attempt, so remained an informal patient. His carers were prevented from visiting him, in case he would want to go home with them. His carers took the case to court, claiming a breach of HL’s rights under the European Convention on Human Rights. The European Court of Human Rights held that HL had been deprived of his liberty and that this was contrary to Article 5 of the European Convention on Human Rights. The regulatory structures in effect at that time were insufficiently robust to meet the requirements of Article 5. This lack of regulation has come to be known as the ‘Bournewood gap’, based on the name of the case in the domestic courts, prior to the Strasbourg reference.

254. Toby Williamson of the Mental Health Foundation and former co-chair of the Making Decisions Alliance, a campaign in support of the introduction of mental capacity legislation at the time the Act was passed, told us 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”.⁴⁶⁷ This was not delivered, he said, because the safeguards “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

⁴⁶⁵ Q 25.

⁴⁶⁶ *HL v The United Kingdom* [2004] (2005) 40 EHRR 32.

⁴⁶⁷ Q 49.

Act”.⁴⁶⁸ Indeed, recent research commissioned by the Department of Health found that the interface between the Mental Health Act and the safeguards was poorly understood by practitioners in part because “the principles and scope of, and criteria for, the MHA and the MCA are fundamentally different ...the MCA is based around principles of autonomy, empowerment, and the importance of supporting decision-making capacity as far as possible; the MHA is not”.⁴⁶⁹ As Dr Allen of the College of Social Work commented, the “two bits of legislation” did not easily fit together because “they come out of different legal and philosophical routes..and have very different histories”.⁴⁷⁰

255. The safeguards apply only to deprivations of liberty in care homes and hospitals. Any other deprivation of liberty based on mental incapacity must be approved directly by the Court of Protection. The provisions require the manager of the hospital or care home to apply to a ‘supervisory body’ (now the local authority) for an authorisation of any suspected deprivation of liberty. The supervisory body sends out assessors who determine whether to grant the application with reference to a set of ‘qualifying requirements’ contained in schedules A1 and 1A to the Act, including the best interests requirement, which largely mirrors the best interests test in the main body of the Act, and the ‘eligibility’ requirement, which delineates between the use of the safeguards and the Mental Health Act 1983. A Relevant Person’s Representative (RPR) is appointed to keep in contact with the person and support them in, for example, triggering a review of the authorisation or making an application to the Court of Protection to challenge an authorisation. In some cases an Independent Mental Capacity Advocate will also be appointed (see chapter 5). The Care Quality Commission has a statutory role to monitor and report on the use of the safeguards, which we address in chapter 4. We have made recommendations concerning access to advocacy in chapter 5, and concerning access to the Court of Protection and the availability of non-means tested legal aid in deprivation of liberty cases in chapter 6. This chapter considers the remaining issues concerning the safeguards.

Overview of findings

256. **Despite the clear intention from Government to close the ‘Bournewood gap’, our evidence suggests that the Deprivation of Liberty Safeguards are frequently not used when they should be, leaving individuals without the safeguards Parliament intended.**
257. **The level and breadth of criticism of the Deprivation of Liberty Safeguards, including from the judiciary, demonstrates that the legislation is not fit for purpose. Better implementation would not be sufficient to address the fundamental problems identified.**
258. **We therefore recommend that the Government undertake a comprehensive review of the DoLS legislation with a view to replacing**

⁴⁶⁸ *Ibid.*

⁴⁶⁹ Clare, I.C.H., Redley, M., Keeling, A., Wagner, A.P., Wheeler, J.R., Gunn, M.J. and Holland, A.J., *Understanding the interface between the Mental Capacity Act’s Deprivation of Liberty Safeguards (MCA-DoLS) and the Mental Health Act (MHA)*, Cambridge Intellectual & Developmental Disabilities Research Group, Department of Psychiatry, University of Cambridge, July 2013, p. 68.

⁴⁷⁰ Q 152.

it with provisions that are compatible in style and ethos with the Mental Capacity Act. The model of widespread consultation that preceded the Mental Capacity Act itself should be followed, with adequate time allowed for effective Parliamentary scrutiny.

259. **We further recommend that the independent body with responsibility for oversight and coordination of implementation of the Mental Capacity Act develop a comprehensive implementation action plan to accompany new legislation, in consultation with professionals, individuals, families and unpaid carers.**
260. We set out our findings in detail and make further recommendations concerning the replacement legislative provisions throughout this chapter.

Use of the Deprivation of Liberty Safeguards

261. The Government predicted that the number of people who would need to be deprived of their liberty for the purposes of treatment or care would be “relatively small”.⁴⁷¹ However, the figures provided in the regulatory impact assessment appear contradictory: 50,000 individuals were identified as likely to be at risk of assessment under the safeguards, but the Government simultaneously suggested a worst case scenario of only 21,000 being subject to an assessment. The number of applications was expected to be higher than necessary initially, but once understanding had developed “about deprivation of liberty and how to avoid it” the numbers would fall.⁴⁷²
262. In contrast to Government predictions, the number of applications was initially low, with only 7,157 in 2009/10, rising to 11,887 in 2012/13, just over half of which were authorised. Although this represented a 66% increase in applications, it was still far below the number originally anticipated by the Government.⁴⁷³ The Alzheimer’s Society considered even the recent higher figures as suspiciously low when compared to the 200,000 people with dementia living in care homes, and the “large number” likely to go into hospital in the course of the year.⁴⁷⁴ The quarterly snapshots show that the highest number of authorisations in place at any one time in 2012/13 was 1,607.⁴⁷⁵ Liberty believed that “thousands, if not tens of thousands, are being de facto detained unlawfully” as a result of a failure to make applications.⁴⁷⁶ This view was not universal: the National Care Association, having expected far fewer applications, expressed surprise at “how many DoLS have been applied for and how many have been granted.”⁴⁷⁷
263. The National Care Association was among many witnesses to express concern at the regional variations in application rates, which they suggested

⁴⁷¹ Ministry of Justice and Department of Health, Impact Assessment of the Mental Capacity Act 2005 deprivation of liberty safeguards to accompany the Code of Practice and regulations, May 2008, p. 9.

⁴⁷² *Ibid.*

⁴⁷³ Health and Social Care Information Centre, *Mental Capacity Act 2005, Deprivation of Liberty Safeguards Assessments (England): Annual Report, 2012/13*, August 2013, p.9
<http://www.hscic.gov.uk/catalogue/PUB11379/DoLSAnnualReport201213.pdf>.

⁴⁷⁴ Alzheimer’s Society.

⁴⁷⁵ Health and Social Care Information Centre, August 2013, *Op. Cit.*, p.11.

⁴⁷⁶ Q 34.

⁴⁷⁷ Q 241.

reflected “real regional variations about interpretation of the law”.⁴⁷⁸ The figures published by the Health and Social Care Information Centre confirm significant regional differences in application rates (figures shown are for applications completed per 100,000 adults). In 2012/13 the East Midlands had an application rate of 48.6, the South West of 37.7 and the North East of 35.7. At the other end of the scale London had a rate of 14.1, Yorkshire and Humber of 22.8 and the North West of 24.6. The overall rate in England was 28.3.⁴⁷⁹ Application rates varied substantially with ethnic group. Rates were highest among the white population (30.4) and lowest among the Asian and Asian British population (8).⁴⁸⁰

264. The Mental Health Alliance argued that “implementation has been extremely uneven, with the result that the protections the scheme is supposed to afford to vulnerable people are effectively unavailable in large parts of the country”.⁴⁸¹ Mencap shared these concerns.⁴⁸² The Care Quality Commission suggested that varying levels of understanding of the Act across providers and commissioners of services could be a factor underlying the regional variations.⁴⁸³ In its most recent report on the safeguards the CQC expressed concern that “instances of unlawful deprivation of liberty may not be recognised by providers or commissioners.”⁴⁸⁴
265. While acknowledging that regional variation may reflect differences in understanding of the safeguards, the Department of Health argued that some variation was inevitable because “some areas have higher populations of older people, some areas have more hospitals and more care homes and some care homes have higher populations of people with dementia.”⁴⁸⁵ What the figures do not reveal is whether practice is good or poor. Mr Neary pointed to the conundrum presented by the data: “If you have two neighbouring boroughs and, say, one has authorised two DoLS and the next borough has authorised 52 ... is two good, or is 52 good?”⁴⁸⁶
266. Nicola Mackintosh suggested that the low number of applications reflected the compliant nature of many incapacitated adults:
- “if you have a vulnerable person detained in a care home who is physically or verbally expressing a wish to leave, those cases are more likely to be raised before the court than cases involving a compliant, incapacitated person. That was the case in the Bournemouth case. I do not think the DoLS scheme has cured the illegality”.⁴⁸⁷
- Joanna Burton concurred, saying that those who are compliant “are rarely considered potential ‘candidates’” for the safeguards.⁴⁸⁸ Similar views were

⁴⁷⁸ Q 24. Others who expressed concerns included: Browne Jacobson Solicitors LLP; Professor Phil Fennell and Dr Lucy Series.

⁴⁷⁹ Health and Social Care Information Centre, August 2013, *Op. Cit.*, p.16.

⁴⁸⁰ Health and Social Care Information Centre, August 2013, *Op. Cit.*, *Op. Cit.*, p.20.

⁴⁸¹ Mental Health Alliance.

⁴⁸² Mencap.

⁴⁸³ Care Quality Commission.

⁴⁸⁴ Care Quality Commission, January 2014, *Op. Cit.*, p. 18.

⁴⁸⁵ Q 15.

⁴⁸⁶ Q 268.

⁴⁸⁷ Q 35.

⁴⁸⁸ Joanna Burton.

expressed by Paul Farmer of Mind⁴⁸⁹ and by Articulate Advocacy.⁴⁹⁰ Most worryingly, Jonathan Senker, of VoiceAbility, told us that “I do not know whether the decision-making around L, the man at the heart of Bournewood, would be different now than it was when he was detained”.⁴⁹¹

267. Confusion over the interface with the Mental Health Act appeared to be another reason for the low number of applications. Advocacy in Action reported that poor understanding of the Mental Capacity Act among mental health professionals had led to the use of detention powers under the Mental Health Act instead of the safeguards.⁴⁹² Alzheimer’s Society reported “a clear lack of understanding of when to use the Mental Health Act and when to use the Mental Capacity Act”, citing enquiries to their helpline from individuals whose family member had been sectioned under the Mental Health Act when the safeguards should have been used.⁴⁹³ London Borough of Camden reported that confusion about the interface between the two pieces of legislation had resulted in low rates of applications under the safeguards from mental health wards; as a result “it is likely that there are a number of people in these types of settings who lack capacity, but who are not subject to any regime, and whose rights are not being protected in any way”.⁴⁹⁴
268. A local authority MCA and MCA DoLS Team illustrated the point by asking for clearer guidance on whether a DoLS assessment was required in a case strikingly similar to that of HL: “an incapacitated and informal patient (not detainable under the Mental Health Act and not able to give valid consent to be an inpatient either but compliant) in a psychiatric ward setting but not free to leave until such time a suitable placement is found”.⁴⁹⁵ Despite the clear intention for the safeguards to apply in exactly such circumstances, questions clearly remain in the minds of professionals.
269. The Minister for Care and Support, Norman Lamb MP, told us that the Bournewood gap had been addressed in legislation, but acknowledged that “not all care homes and hospitals understand fully when the DoLS should be used. Further work is needed in this area”.⁴⁹⁶
270. **We are concerned that there is a very real risk that the Deprivation of Liberty Safeguards are frequently not used when they should be, leaving individuals without the safeguards Parliament intended, and leaving care providers vulnerable to legal challenge.**

Criticisms of the legislation

271. While the Mental Capacity Act was generally described as “sound and innovative legislation”⁴⁹⁷ the DoLS were viewed as “hugely complex, voluminous, overly bureaucratic, difficult to understand and yet [providing]

⁴⁸⁹ Q 95.

⁴⁹⁰ Articulate Advocacy.

⁴⁹¹ Q 119.

⁴⁹² Advocacy in Action.

⁴⁹³ Alzheimer’s Society.

⁴⁹⁴ Housing and Social Care Services, London Borough of Camden.

⁴⁹⁵ MCA and MCA DoLS’ Team of Cambridgeshire County Council.

⁴⁹⁶ Letter from Norman Lamb MP, Minister for Care and Support, 9 December 2013. See appendix 6.

⁴⁹⁷ Cambridge Intellectual and Developmental Disabilities Research Group, Department of Psychiatry, University of Cambridge.

mentally incapacitated people with minimum safeguards”.⁴⁹⁸ The House of Commons Health Select Committee, in August 2013, described evidence it received on the safeguards as “profoundly depressing and complacent”, stating that “despite fine words in legislation” vulnerable individuals “are currently widely exposed to abuse because the controls which are supposed to protect them are woefully inadequate”.⁴⁹⁹ Mr Justice Charles, Vice-President of the Court of Protection, described the experience of writing a judgment on the safeguards as feeling “as if you have been in a washing machine and spin dryer”.⁵⁰⁰

272. There was, nevertheless, support for the purpose underlying the safeguards. The Law Society argued that, where implemented properly, their use encouraged “managing authorities to put greater thought into planning how they deliver care, and to avoid blanket restrictions”.⁵⁰¹ Mr Neary said that without the safeguards and the ability to challenge the authorisation in the Court of Protection “Steven would now be in that care home in Wales that Hillingdon intended to send Steven to”.⁵⁰² (See Box 3 in chapter 3). But it was equally clear from the evidence we have received that the purpose behind the safeguards was not being consistently achieved.

Why are the safeguards not working in practice?

Failure to apply the principles

273. The Care Quality Commission argued that the primary issue was one of a lack of understanding of the Act: “If the ‘5 key principles’ and the concepts of ‘capacity’ and ‘best interests’ ... are properly understood by those working at all levels of the health and social care system then the ... Safeguards would be adequate”.⁵⁰³ Evidence suggested, however, that this connection was rarely made, and Irwin Mitchell LLP argued that “poor understanding of capacity assessments and best interests decision making applies in relation to the DoLS safeguards as much as it does in relation to any other best interests decision”.⁵⁰⁴ It was further suggested that the safeguards were often seen as “a need for authorities to set up paperwork processes to make restrictions on a person ‘legal’, rather than ... actual and real safeguards for people”.⁵⁰⁵ Significant criticisms were made of the failure to apply the ‘less restrictive option’ principle in relation to the safeguards.⁵⁰⁶

⁴⁹⁸ Q 25, Professor Jones. Also supported by: MM; South West IMCA Group; British Association of Social Workers.

⁴⁹⁹ Health Select Committee, *Post-legislative scrutiny of the Mental Health Act 2007* (1st Report of Session 2013–14, HC 584), para 106
<http://www.publications.parliament.uk/pa/cm201314/cmselect/cmhealth/584/584.pdf>.

⁵⁰⁰ Q 293.

⁵⁰¹ The Law Society.

⁵⁰² Q 260.

⁵⁰³ Care Quality Commission.

⁵⁰⁴ Irwin Mitchell LLP.

⁵⁰⁵ 3 Counties IMCA Service.

⁵⁰⁶ Kent and Medway MCA Local Implementation Network; 3 Counties IMCA Service; Advocacy Support Cymru; Q 87 (Beverley Dawkins, Mencap).

274. **We recommend that replacement legislative provisions make a clear link to the principles of the Mental Capacity Act to ensure consistency with the empowering ethos of the Act as a whole.**

Complexity

275. Perhaps the most frequent criticism of the safeguards was their complexity and bureaucracy. The 3 Counties IMCA service reported that: “The experience for the person and his or her family can be one of difficulty in understanding what is happening, further alienation, and ... distress in an already distressing situation”, while for professionals it “can often be bewilderment, discord, and stress”.⁵⁰⁷ Bracknell Forest Council, Age UK Devon, London Borough of Camden and Lancashire County Council DoLS Team all raised concerns regarding the standard forms, viewing them as lengthy, overly numerous and needing redesign in a more accessible format.⁵⁰⁸ Independent research commissioned by the Department of Health concurred and recommended a redesign of the standard forms.⁵⁰⁹
276. The complexity of the eligibility criteria governing the interface with the Mental Health Act 1983, set out in schedule 1A to the Act, was subject to much criticism and, as already noted above, appeared to result in the safeguards not being applied when they should be.⁵¹⁰ Derek Boothby, a Best Interests Assessor and Approved Mental Health Professional, argued that “the interface issues challenge even the most astute and knowledgeable, the impenetrable nature of the schedules relating to the MCA do not help in this respect, any legal challenge in this area seems to add to the confusion rather than helping it”.⁵¹¹ Camden Adult Safeguarding Board said that the criteria caused “confusion and conflict” among professionals, highlighting a difference in thresholds between the safeguards and mental health legislation.⁵¹² Professor Fennell and Dr Series argued that the overlap of eligibility created unnecessary difficulties and uncertainties in decisions about care,⁵¹³ while Serjeants’ Inn Chambers argued for an “overhaul” of Schedule 1A, which they considered “far too complex” and “lacking in clarity”.⁵¹⁴ They also pointed to a new gap created by attempts to prevent overlap with the Mental Health Act,⁵¹⁵ which we consider below (paragraphs 298-300).
277. **We recommend that replacement legislative provisions and associated forms be drafted in clear and simple terms, to ensure they can be understood and applied effectively by professionals, individuals, families and carers.**

⁵⁰⁷ 3 Counties IMCA service.

⁵⁰⁸ Bracknell Forest Council; Age UK Devon; Housing and Social Care Services, London Borough of Camden; Lancashire County Council DoLS Team.

⁵⁰⁹ Clare, I.C.H., Redley, M., Keeling, A., Wagner, A.P., Wheeler, J.R., Gunn, M.J. and Holland, A.J., *Op. Cit.* July 2013, p. 70.

⁵¹⁰ For example, Serjeants’ Inn Chambers; Richard Tucker (Rotherham, Doncaster, and South Humber Mental Health NHS Foundation Trust); Q 35.

⁵¹¹ Derek Boothby AMHP/ BIA.

⁵¹² Camden Safeguarding Adults Partnership Board.

⁵¹³ Professor Phil Fennell and Dr Lucy Series.

⁵¹⁴ Serjeants’ Inn Chambers.

⁵¹⁵ Serjeants’ Inn Chambers; Official Solicitor to the Senior Courts.

278. **We note that the Code of Practice to the Mental Health Act 1983 is due for review in 2014. Clarification on the relationship between the Mental Capacity Act and the Mental Health Act is urgently required to assist practitioners.**

A definition?

279. Many witnesses called for a statutory definition of ‘deprivation of liberty’ to provide greater clarity and certainty.⁵¹⁶ The Act ties the definition to that of the European Convention on Human Rights. Section 64 (5) MCA states that “in this Act, references to deprivation of a person’s liberty have the same meaning as in Article 5(1) of the Human Rights Convention.” This applies whether or not the deprivation is carried out by a public body.⁵¹⁷ The Human Rights Act 1998 also requires the courts to take account of decisions of the European Court of Human Rights in determining any question relating to a convention right.⁵¹⁸
280. Nevertheless, the definition that has been developed by the courts was considered by Liberty to be narrower than that required by Article 5 of the European Convention.⁵¹⁹ Liberty further suggested that the explanation contained in the Code of Practice to the safeguards was out of date, following at least 16 published judgments on the meaning of deprivation of liberty.⁵²⁰ The absence of a final judgment in the case of *Cheshire West and Chester Council v P*,⁵²¹ concerning what constitutes a deprivation of liberty and currently under consideration by the Supreme Court, added to the uncertainty.⁵²²
281. Underlying some of the calls for a definition appeared to be a lack of consistency, with care homes receiving conflicting messages from different assessors. Elmari Bishop reported that “We will go to our hospitals and care homes and say, ‘This is what you need to look out for’, and then a best-interest assessor might come and assess someone and give them a completely different message”.⁵²³
282. The Government indicated that they would review the issue of a definition following the decision of the Supreme Court.⁵²⁴ However, the Government’s memorandum argued against a statutory definition as this allowed the safeguards to keep in step with developments in the case law of the European Court of Human Rights under Article 5. Furthermore, “a statutory definition could not simply address the complex facts in individual cases”.⁵²⁵ The Official Solicitor agreed, explaining that “the interpretation of Article 5 by the European Court of Human Rights is the relevant interpretation.” This meant that it was not possible to freeze the definition of deprivation of

⁵¹⁶ Alzheimer’s Society; Bracknell Forest Council; The College of Emergency Medicine; Liberty.

⁵¹⁷ Mental Capacity Act 2005, section 64 (6).

⁵¹⁸ Human Rights Act 1998, section 2.

⁵¹⁹ Q 41.

⁵²⁰ Liberty.

⁵²¹ *Cheshire West and Chester Council v P* [2011] EWCA Civ 1257.

⁵²² British Psychological Society; Irwin Mitchell LLP; Browne Jacobson Solicitors LLP.

⁵²³ Q 263.

⁵²⁴ Ministry of Justice and Department of Health.

⁵²⁵ *Ibid.*

liberty, as any definition would be subject to the evolving case law of that court.⁵²⁶

283. **We agree with the Government and the Official Solicitor that no statutory definition of “deprivation of liberty” is currently required. While the lack of a definition may reduce certainty, the term was intended to echo the wording of Article 5 of the European Convention on Human Rights, and the current statutory provisions are adequate to achieve this. At the same time, action is clearly needed to assist health and social care practitioners in identifying such a deprivation. We address training and awareness raising in chapter 4.**

Unhelpful nomenclature

284. The term ‘deprivation of liberty’ was itself proposed as a cause of under-use of the safeguards. The Department of Health argued that “People concentrate on saying ‘deprivation of liberty’ when what they should be concentrating on is the word ‘safeguards’”, this distracted from the purpose of ensuring “that people who in their best interest have some restrictions on their liberty ... have adequate recourse and protection within the law and within the system”.⁵²⁷ The Mental Health Alliance advocated the term ‘Protective Care’ as having more positive connotations,⁵²⁸ a phrase also endorsed by Browne Jacobson who suggested that the current terminology resulted in an “inherent reluctance” on the part of providers to identify a deprivation of liberty.⁵²⁹
285. **The term ‘deprivation of liberty’ is unhelpful, but it may not be possible to eliminate its use even with replacement provisions, given that it derives from Article 5 of the European Convention on Human Rights. Better understanding of the purpose behind the safeguards is urgently required, and we recommend that achieving this be made a priority by the independent oversight body.**

The effectiveness of the Relevant Person’s Representative role

286. A further difficulty reported with the application of the safeguards was the reliance on the role of Relevant Person’s Representative, or RPR. Witnesses criticised the fact that the choice of RPR was left to the local authority, with reports that family members were often not appointed if they were already in conflict with the statutory body,⁵³⁰ and that there was often a failure to inform an unpaid RPR of the availability of an independent mental capacity advocate.⁵³¹
287. Even where the role was operating as intended, problems were reported with the ability of unpaid RPRs to challenge an authorisation. A detailed illustration was provided in a submission from a private individual, MM, who

⁵²⁶ Q 271.

⁵²⁷ Q 14.

⁵²⁸ Mental Health Alliance.

⁵²⁹ Browne Jacobson Solicitors LLP.

⁵³⁰ Mr and Mrs E (the carers for HL who brought the Bournemouth case); Victoria Butler-Cole, Neil Allen, Andrew Bowmer, Julie Cornes, Charlotte Haworth Hird, Laura Hobey-Hamsher, Laura Jolley, John McKendrick, Alex Ruck Keene, Polly Sweeney, Rachel Turner and Paula Scully.

⁵³¹ *Ibid.*

recounted the experiences of an 89 year-old woman who acted as unpaid RPR for a friend. She reported feeling that “the full force of the state was battling against her” and that she faced constant suspicion and disadvantage when challenging the local authority. Her attempt to challenge an authorisation for a deprivation of liberty through the Court of Protection was described as “complex and harrowing”, even with the provision of legal aid.⁵³² On a more positive note, Nicola Mackintosh reported that she had “experience of cases that have come to court because the RPR, on behalf of the incapacitated person, has made the application or has assisted the person to make the application to court”.⁵³³

288. **In principle the establishment of the role of the Relevant Person’s Representative has been positive. However it does not always provide an effective safeguard for P’s rights when challenging local authorities. We recommend that the Government consider how the role could be strengthened in replacement legislative provisions to provide an effective safeguard.**

The effectiveness of the supervisory body role

289. The Care Quality Commission identified variation in how supervisory bodies discharged their functions, including how they support care homes and hospitals, their relationship with safeguarding teams and how they work with advocates.⁵³⁴ Professor Jones told us that “some cases indicate that DoLS has been used as an instrument of oppression, where local authorities acting as supervisory bodies have used DoLS to get their way”.⁵³⁵ Mr Neary said that the safeguards were “turned on [their] head” by London Borough of Hillingdon.⁵³⁶

“Safeguards were in place but Steven wasn’t allowed to come home; plans were being made to move him 200 miles away; all his activities that give him his quality of life had been stopped; and his important relationships, especially with me, were being severely curtailed. There didn’t appear to be anything that was happening that even remotely resembled a safeguard”.⁵³⁷

290. A potential conflict of interests was identified by Stephen Ward of the Isle of Wight Council and NHS Foundation Trust, who argued that “there is an inherent conflict of interest for [local authorities] as Supervisory Bodies and Commissioners of the care that results in deprivation of liberty”.⁵³⁸ However, there was evidence of good practice in the positive use of the commissioning role, provided by ADASS (see paragraphs 144–145).⁵³⁹ Nevertheless, it does not appear that such an approach is widespread.
291. There is also a possible gap in the regulatory regime, given that the Care Quality Commission does not regulate the supervisory body. The CQC

⁵³² MM.

⁵³³ Q 35.

⁵³⁴ Care Quality Commission.

⁵³⁵ Q 25.

⁵³⁶ Q 260.

⁵³⁷ Mark Neary.

⁵³⁸ Stephen Ward (Isle of Wight Council and NHS Foundation Trust).

⁵³⁹ Association of Directors of Adult Social Services (ADASS).

recognised this and was undertaking collaborative work with supervisory bodies to improve national understanding in the absence of specific inspection powers (see paragraphs 120-124).⁵⁴⁰

292. **The evidence suggests that supervisory bodies are not consistently providing the safeguard intended, indicated in part by the regional variations in how they discharge their functions.**
293. **We recommend that effective oversight of any future supervisory body function be provided for in the replacement provisions for the Deprivation of Liberty Safeguards.**

Potential new gaps

294. Many witnesses pointed to a gap in protection for those who may be deprived of their liberty while living in supported accommodation. This issue has become more important in recent years as a result of the policy shift away from care homes to community-based accommodation.⁵⁴¹ The safeguards apply only to hospitals and care homes. Deprivation of liberty of those living in supported accommodation need to be authorised directly by the Court of Protection. The Mental Health Alliance argued that those in supported living were no “less vulnerable to inadequate or abusive care, or to being deprived of their liberty, than are people in registered care homes. Indeed, they may be more vulnerable, since the actual living arrangements are not currently inspectable by the CQC and are therefore effectively unregulated”.⁵⁴² This view was supported by Liberty,⁵⁴³ POhWER⁵⁴⁴ and the Law Society.⁵⁴⁵
295. In response to such concerns, Mr Lamb told us that, while he might revisit this area in the future, he was “content that local authorities should seek authorisation from the Court of Protection”⁵⁴⁶ when a deprivation of liberty was indicated in supported living accommodation.
296. **Vulnerable adults living in supported accommodation are at risk of being unlawfully deprived of their liberty because they fall outside the scope of the Deprivation of Liberty Safeguards. Although recourse to the Court of Protection is available, evidence of the barriers individuals face in accessing the Court, and of the failure by local authorities to bring cases to Court when necessary, suggests that this is unlikely to provide the safeguards intended.**
297. **We recommend that replacement legislative provisions extend to those accommodated in supported living arrangements.**

The eligibility criteria and a ‘new Bournemouth gap’?

298. We have touched on the criticism that the eligibility criteria are overly complex, leading to uncertainty over the relationship with the Mental Health Act 1983. Evidence suggested that this relationship, as set out in section 16A

⁵⁴⁰ Care Quality Commission.

⁵⁴¹ The Law Society; London Borough of Newham Adults Social Care; British Psychological Society.

⁵⁴² Mental Health Alliance.

⁵⁴³ Liberty.

⁵⁴⁴ POhWER.

⁵⁴⁵ The Law Society.

⁵⁴⁶ Letter from Norman Lamb MP, Minister for Care and Support, 9 December 2013. See appendix 6.

and Schedule 1A, had also given rise to a potential gap in protection described as “every bit as troublesome as that identified in the Bournemouth case itself”.⁵⁴⁷ A case demonstrating this concerned a man, Dr A, detained in hospital under section 3 of the Mental Health Act, who went on hunger strike in an attempt to recover his passport, confiscated by the UK Border Agency. The court found that Dr A lacked capacity and that it was in his best interests to be force-fed, entailing a deprivation of his liberty that would normally be authorised under the Mental Capacity Act. However, as he was already detained under the Mental Health Act he was ineligible for the Deprivation of Liberty Safeguards; nor could the force-feeding be authorised under the Mental Health Act since it concerned treatment for a physical condition with insufficient connection to his mental disorder. The case was resolved through the use of the inherent jurisdiction of the Court.

299. Serjeants’ Inn Chambers argued that this made a clear case for the reform of the eligibility criteria “permitting in appropriate cases the deprivation of liberty of a person lacking relevant capacity, for the purpose of medical treatment which is separate from the person’s mental disorder”.⁵⁴⁸ This would be sufficient to close the gap. A similar recommendation was made by the Official Solicitor.⁵⁴⁹ Mr Lamb disagreed, arguing that, in light of the inherent jurisdiction of the Court, “there is no gap which requires filling”.⁵⁵⁰
300. **We consider that a ‘new Bournemouth gap’ has been inadvertently created by the attempt to prevent overlap with the Mental Health Act 1983. We recommend that replacement legislative provisions close this gap.**

⁵⁴⁷ Victoria Butler-Cole, Neil Allen, Andrew Bowmer, Julie Cornes, Charlotte Haworth Hird, Laura Hobey-Hamsher, Laura Jolley, John McKendrick, Alex Ruck Keene, Polly Sweeney, Rachel Turner and Paula Scully.

⁵⁴⁸ Serjeants’ Inn Chambers.

⁵⁴⁹ Q 272.

⁵⁵⁰ Letter from Norman Lamb MP, Minister for Care and Support, 9 December 2013. See appendix 6.

CHAPTER 8: CRIMINAL LAW PROVISIONS

301. Section 44 of the Mental Capacity Act 2005 introduced a criminal offence of ill treatment or neglect of a person who lacks capacity. Where the ill treatment or neglect is by a person (D) who has the care of the person concerned (P), rather than a court appointed deputy or donee of a lasting power of attorney, the Act requires P to lack capacity or D to have a reasonable belief that P lacks capacity.

BOX 8

Ill-treatment or neglect

- (1) Subsection (2) applies if a person (“D”)—
 - (a) has the care of a person (“P”) who lacks, or whom D reasonably believes to lack, capacity,
 - (b) is the donee of a lasting power of attorney, or an enduring power of attorney (within the meaning of Schedule 4), created by P, or
 - (c) is a deputy appointed by the court for P.
- (2) D is guilty of an offence if he ill-treats or wilfully neglects P.
- (3) A person guilty of an offence under this section is liable—
 - (a) on summary conviction, to imprisonment for a term not exceeding 12 months or a fine not exceeding the statutory maximum or both;
 - (b) on conviction on indictment, to imprisonment for a term not exceeding 5 years or a fine or both

302. In 2012, 85 cases were brought under section 44 of the Act, 36 resulting in guilty verdicts. This represents a significant increase on 2008, which saw 36 cases brought and 7 guilty verdicts.⁵⁵¹ Nevertheless, this figure seems low, in the context of 800,000 people with dementia⁵⁵² and 1.5 million people with learning disabilities⁵⁵³ in the UK, a significant number of whom are likely to come within the remit of the Mental Capacity Act at some point in their lives.
303. The Government told us that they did not hold details of the exact nature of the offences prosecuted, which could not be obtained without disproportionate cost. But “from evidence recently collated from media articles” they have suggested that section 44 of the Mental Capacity Act is “being used to prosecute those who have the care of the person lacking capacity”, whereas “the Fraud Act is being used to prosecute where attorneys and deputies have abused their position and misappropriated funds”⁵⁵⁴. We question the suitability of reliance on media reports to assess the use of the

⁵⁵¹ Ministry of Justice and Department of Health.

⁵⁵² Figures taken from the Department of Health Dementia Challenge. <http://dementiachallenge.dh.gov.uk/2012/05/22/about-dementia/>.

⁵⁵³ Mencap.

⁵⁵⁴ Letter from Lord McNally, Minister of State for Justice, 10 December 2013. See appendix 7.

- section 44 offence, given that it was widely reported that staff at Winterbourne View were prosecuted under the Mental Capacity Act, when this was not the case. Lord McNally acknowledged that “clearly there is work to be done to ensure that more use is made of the offence” in the Act. He stated that his officials “will further discuss the matter” with the Crown Prosecution Service and contact the Association of Chief Police Officers”.⁵⁵⁵
304. Witnesses suggested that underuse of section 44 may, in part, be due to drafting as well as operational concerns. The decision and time specific nature of capacity assessment, along with the presumption of capacity, are a defining feature of the Act, but appeared to create problems when applied to the question of capacity in section 44.⁵⁵⁶ A group of solicitors and barristers explained that “clarification is required on the face of the statute as to what, exactly, the person said to lack capacity in s.44(1)(a) is required to lack capacity to decide—it is a meaningless statement to say that someone lacks capacity”.⁵⁵⁷
305. This echoes judicial criticism of section 44. The former Lord Chief Justice, Lord Judge, in *R v Dunn*,⁵⁵⁸ suggested that the provisions “do not appear to be entirely appropriate to defining the constituent elements of the criminal offence”⁵⁵⁹. Similar criticisms were made in *R v Hopkins* and *R v Priest*,⁵⁶⁰ and *Ligaya Nursing v R*.⁵⁶¹ In *R v Hopkins* and *R v Priest* Lord Justice Pitchford stated that “Unconstrained by authority, this court would be minded to accept the submission ... that Section 44(1)(a) ... is so vague that it fails the test of sufficient certainty” required of a criminal offence.⁵⁶²
306. The Law Society of Scotland, noting these criticisms, pointed out that the equivalent Scottish offence, contained in the Adults with Incapacity (Scotland) Act 2000, does not require any element of incapacity. Section 83(1) of that Act provides that: “It shall be an offence for any person exercising powers under this Act relating to the personal welfare of an adult to ill-treat or wilfully neglect that adult”. They added that they were aware of “no suggestion that the wording of this section is inappropriate or that there ought to be a requirement to establish an additional element of incapacity”.⁵⁶³
307. Lord McNally acknowledged these concerns and showed a willingness to “explore further with the Crown Prosecution Service whether there are significant issues with the requirement for assessment of mental capacity that might affect how this section of the Act is being used”.⁵⁶⁴
308. **We welcome the Government’s commitment to discuss with the Crown Prosecution Service and the Association of Chief Police**

⁵⁵⁵ *Ibid.*

⁵⁵⁶ Worcester County Council.

⁵⁵⁷ Victoria Butler-Cole, Neil Allen, Andrew Bowmer, Julie Cornes, Charlotte Haworth Hird, Laura Hobeys-Hamsher, Laura Jolley, John McKendrick, Alex Ruck Keene, Polly Sweeney, Rachel Turner and Paula Scully.

⁵⁵⁸ *R v Dunn* [2010] EWCA Crim 2935.

⁵⁵⁹ *Ibid.*, paragraph 19.

⁵⁶⁰ *R v Hopkins and R v Priest* [2011] EWCA Crim 1513.

⁵⁶¹ *Ligaya Nursing v R* [2012] EWCA Crim 2521.

⁵⁶² *R v Hopkins and R v Priest* [2011] EWCA Crim 1513, paragraph 40.

⁵⁶³ The Law Society of Scotland.

⁵⁶⁴ Q 317.

Officers the need to ensure appropriate use is made of section 44 of the Mental Capacity Act. We request that specific information on this be provided in the Government response to this Report.

309. **We recommend that the Government initiate a review of whether the offence in section 44 of the Act meets the test of legal certainty; and if it does not, to bring forward new legislative provisions. The results of this review should be published within 12 months of publication of our Report.**

APPENDIX 1: LIST OF MEMBERS AND DECLARATIONS OF INTEREST

Members

The Lord Alderdice
 The Baroness Andrews OBE
 The Baroness Barker
 The Baroness Browning
 The Lord Faulks (until 18 December 2013)
 Rt Hon the Lord Hardie (Chairman)
 Professor the Baroness Hollins
 The Baroness McIntosh of Hudnall
 Professor the Lord Patel of Bradford OBE
 Rt Hon the Baroness Shephard of Northwold
 The Lord Swinfen
 The Lord Turnberg

Declared Interests

The Lord Alderdice
Retired Consultant Psychiatrist in Psychotherapy
Patron, Northern Ireland Institute of Human Relations
President, Westminster Pastoral Foundation
Hon Fellow, Royal College of Psychiatrists
Hon Affiliate, British Psychoanalytical Society
Patron, Youth Access UK
Patron, ICAP (Irish Immigrant Psychotherapy Organization)
Vice-President, National Benevolent Fund for the Aged

The Baroness Andrews OBE
Former Government spokesperson for Health (2002-05), Work and Pensions (2002-05), Education and Skills (2003-05)

The Baroness Barker
Owner, ThirdSectorBusiness (a company that works extensively with a wide range of national, regional and local charities)
Consultant, B&W Consulting (a company that works extensively with a wide range of national, regional and local charities)

The Baroness Browning
Vice-President, National Autistic Society
Patron, Research Autism
Vice-President, Alzheimer's Society
Patron, Action on Elder Abuse
Named Carer of a man living independently with Asperger syndrome

The Lord Faulks (until 18 December 2013)
Barrister (occasionally deals with issues involving the Mental Capacity Act)

Rt Hon the Lord Hardie
Honorary President, Capability Scotland (a charity which campaigns on behalf of and provides services in Scotland for adults and children with multiple and complex needs due to mental and/or physical disabilities.)

Professor the Baroness Hollins

Parent of an adult man with a learning disability who uses services funded by the local authority

Past President and Fellow of the Royal College of Psychiatrists

Retired Consultant Psychiatrist in Learning Disability

Emeritus Professor of Psychiatry of Disability, St George's University of London

Executive Chair of Books Beyond Words Community Interest Company (publishes picture books to support decision-making for adult non-readers)

Chair, Board of Science, British Medical Association

Past President of the British Medical Association

The Baroness McIntosh of Hudnall

Past member of the Pre-legislative Scrutiny Committee which considered the Draft Mental Incapacity Bill in 2003

Professor the Lord Patel of Bradford OBE

Professor and University Director of Strategic Partnerships and Senior Advisor to the Vice Chancellor, University of East London (2011–date)

Professorial Fellow of The Institute of Mental Health Nottingham (2012–date)

Secretary to All Party Parliamentary Group on Prison Health (2010–date)

President of Bradford Magistrates Chaplaincy Service (charity providing support for those engaged in the criminal justice system; 2008–date)

Vice-President and Professorial Fellow of the Royal Society of Public Health

Former Chairman, National Prison Drug Treatment Strategy Review Group (2009–2011)

Former Chairman, Integrated Equality & Human Rights Committee (Leicestershire, Leicester and Rutland) (2010–2012)

Former Government Spokesperson for the Department of Communities & Local Government; Ministry of Justice; Cabinet Office and the Former Attorney General's Office. (Oct 2008–Sept 2009)

Former Shadow Front Bench Minister (Communities), (May 2010–2012)

Former Non Executive Commissioner, Care Quality Commission (2008)

Former Chairman, Mental Health Act Commission (2002–Oct 2008)

Former Member, Department of Health Mental Health Workforce Task Group (2002–2005)

Former National Director, Department of Health Delivering Race Equality in mental health care programme (DRE) and Chairman of DRE Board (2004–2006)

Former Vice-Chairman, Mental Health Act Commission (2001–2002)

Former Non Executive Board Member, Mental Health Act Commission (1995–2001)

Rt Hon the Baroness Shephard of Northwold

No relevant interests declared

The Lord Swinfen

Chairman, The Swinfen Charitable Trust (a charity which provides medical advice to health care professionals overseas)

Fellow, Royal Society of Medicine

The Lord Turnberg

Trustee, Wolfson Foundation

Scientific Advisor–Association of Medical Research Charities

A full list of Members' interests can be found in the Register of Lords Interests:

<http://www.parliament.uk/mps-lords-and-offices/standards-and-interests/register-of-lords-interests/>

Professor Peter Bartlett, Specialist Adviser

Nottinghamshire Healthcare NHS Trust Professor of Mental Health Law, School of Law and Institute of Mental Health, University of Nottingham Appointed by the Council of Europe to advise the Government of Georgia on law in relation to mental disability and persons charged with crime and prisoners (February 2014)

Author, Mental Health Law: Policy and Practice (4th ed., Oxford University Press, 2013)

Author, Blackstone's Guide to the Mental Capacity Act, (2nd ed., Oxford University Press, 2007)

Author, Mental Disability and the European Convention on Human Rights (Martinus Nijhoff, 2006)

Author, Mental Illness, Discrimination and the Law (Wiley-Blackwell, 2012)

Author, The Poor Law of Lunacy (Cassells/University of Leicester Press, 1999)

Co-investigator, Reducing relapse and suicide in bipolar disorder (National Institute of Health Research, RP-PG-0407-10389)

Co-investigator, Characteristics and needs of long-stay patients in high and medium secure forensic-psychiatric care: Implications for service organisation (National Institute of Health Research, Health Services and Delivery Research, 11/1024/06)

Former Honorary Chair, Board of the Mental Disability Advocacy Center (MDAC)

Former Sub-Editor, Journal of Forensic Psychiatry and Psychology

APPENDIX 2: LIST OF WITNESSES

Evidence is published online at <http://www.parliament.uk/mental-capacity-act-2005/> and available for inspection at the Parliamentary Archives (020 7219 5314).

Evidence received by the Committee is listed below in chronological order of oral evidence session and in alphabetical order. Those witnesses marked with * gave both oral evidence and written evidence. Those marked with ** gave oral evidence and did not submit any written evidence. All other witnesses submitted written evidence only.

NB In order to protect individuals, some witnesses are referred to by their initials only.

Oral evidence in chronological order

*	QQ 1–24	Ministry of Justice
*		Department of Health
*	QQ 25–44	The Law Society
*		Liberty
**		Professor Richard Jones, Cardiff Law School
**		Kirsty Keywood, University of Manchester
*	QQ 45–55	Mental Health Foundation
*		Sense
*	QQ 56–73	Dr Pauline Heslop, University of Bristol
**		Dr Margaret Flynn
*	QQ 74–89	Down’s Syndrome Association
*		Mencap
**		National Autistic Society
*	QQ 90–105	Alzheimer’s Society
*		Headway
*		Mind
*	QQ 106–125	Asist
*		POhWER
*		VoiceAbility
*	QQ 126–138	Carers Trust
*		Carers UK
*		National Family Carer Network
*	QQ 139–152	British Association of Social Workers
*		The College of Social Work
*	QQ 153–171	Royal College of General Practitioners
*		Royal College of Psychiatrists

- * College of Emergency Medicine
- * Academy of Medical Royal Colleges
- * British Medical Association
- * QQ 172–184 Association of Directors of Adult Social Services (ADASS)
- * Shropshire County Council
- * QQ 185–196 Social Care Institute for Excellence (SCIE)
- * British Institute of Human Rights
- ** Paul Gantley
- * QQ 197–209 Care Quality Commission
- * QQ 210–220 General Medical Council
- * Health and Care Professions Council
- * QQ 221–235 NHS England
- ** Healthwatch England
- * QQ 236–246 National Care Association
- * QQ 247–259 Alex Ruck Keene, 39 Essex Street Chambers
- * Michael Mylonas, Serjeants’ Inn Chambers
- * Alex Rook and Julia Lomas, Irwin Mitchell LLP
- * QQ 260–269 South Essex Partnership University NHS Foundation Trust (SEPT)
- * Mark Neary
- * QQ 270–280 Official Solicitor to the Senior Courts
- * QQ 281–291 Office of the Public Guardian
- * QQ 292–311 Mr Justice Charles, Vice-President of the Court of Protection
- * Senior Judge Denzil Lush, Senior Judge of the Court of Protection
- ** District Judge Margaret Glentworth
- ** District Judge Elizabeth Batten
- * QQ 312–333 Lord McNally, Minister of State for Justice, Ministry of Justice
- * Norman Lamb MP, Minister of State for Care and Support, Department of Health

Alphabetical list of all witnesses

- 3 Counties IMCA Service
- Dr Julian Abel
- * Academy of Medical Royal Colleges (QQ 153–171)

Advanced Decision Evaluation (ADE) in Bipolar Disorder Study Team,
Institute of Mental Health, University of Nottingham

Advocacy in Action

Advocacy Matters IMCA Service

Advocacy Support Cymru (ASC)

Age UK

Age UK Cheshire Advocacy

Age UK Devon

Aire Centre

Neil Allen

Allied Professional Will Writers

Allied Services Trust

* Alzheimer's Society (QQ 90–105)

Dr Olufunso B. Aribisala

Andy Armstrong

Articulate Advocacy CIC

AS

* Asist (QQ 106–125)

* Association of Directors of Adult Social Services (ADASS)
(QQ 172–184)

Association of Public Authority Deputies

** District Judge Elizabeth Batten (QQ 292–311)

David Beckingham, University of Cumbria

Kate Beynon PSW/ BIA/ AMHP

Mr and Mrs Boff

Professor John Bond

Derek Boothby AMHP/ BIA

Andrew Bowmer

Dr Geraldine Boyle, University of Bradford

Bracknell Forest Council

Brain Injury Rehabilitation Trust

Brighton and Hove City Council

Bristol Mind IMCA Service

British Association of Brain Injury Case Managers

* British Association of Social Workers (QQ 139–152)

* British Institute of Human Rights (QQ 185–196)

British Institute of Learning Disabilities

- ★ British Medical Association (QQ 153–171)
British Psychological Society
Browne Jacobson Solicitors LLP
Joanna Burton
Victoria Butler-Cole
Cambridge House Advocacy Service
Cambridge Intellectual and Developmental Disabilities Research Group, University of Cambridge
Camden Safeguarding Adults Partnership Board
Rosemary Cantwell
- ★ Care Quality Commission (QQ 197–209)
- ★ Carers Trust (QQ 126–138)
- ★★ Carers UK (QQ 126–138)
Professor John Carpenter, University of Bristol
Dr Nick Cartmell
Challenging Behaviour Foundation
- ★ Mr Justice Charles, Vice-President of the Court of Protection (QQ 292–311)
Chartered Institute of Linguists Working Group on Language Support in Health and Social Care
- ★ College of Emergency Medicine (QQ 153–171)
- ★ College of Social Work (QQ 139–152)
Compassion in Dying
Julie Cornes
- ★ Court of Protection (QQ 292–311)
Simon Cramp
DBM
DCJ
Dementia UK
- ★ Department of Health (QQ 1–24, QQ 312–333)
Derbyshire DoLS Team
DGP
Dimensions (UK) Ltd
Dr Andreas Dimopoulos, Brunel University
Disabilities Trust
Doncaster Safeguarding Adults Partnership Board
Dorset Advocacy
- ★ Down’s Syndrome Association (QQ 74–89)

- Michael du Feu
 Mr and Mrs E
 East Sussex County Council
 Peter Edwards
 EE
 Charlotte Emmett
 Empowerment Matters CIC
 Essex Autonomy Project
 Executive Committee of the Eating Disorders Section of the Royal
 College of Psychiatrists (EDSECT)
 Professor Phil Fennell
- ** Dr Margaret Flynn (QQ 56–73)
 Forget-Me-Nots
- ** Paul Gantley (QQ 185–196)
 Dr Martin Gee
- * General Medical Council (QQ 210–220)
 Generate
 Professor Robert George MA MD FRCP
- ** District Judge Margaret Glentworth (QQ 292–311)
 Gloucestershire MCA Governance Group
 Piers Gooding
 Dr Helen Greener
 Hampshire County Council
 Dr Andrew D. Hardie
 Dr Rosie Harding, University of Birmingham
 Haven Lincoln Crisis House
 Charlotte Haworth Hird
 Head First
- * Headway (QQ 90–105)
- * Health and Care Professions Council (QQ 210–220)
 Health Research Authority
- ** Healthwatch England (QQ 221–235)
 John Hemming MP
- * Dr Pauline Heslop, University of Bristol
 David Hewitt
 Donna Hewitt
 Hft

- Laura Hobey-Hamsher
Housing and Social Care Services, London Borough of Camden
Professor Julian Hughes
Human Tissue Authority
IMCA Service in Rochdale and District Mind
Institute of Professional Willwriters
- * Irwin Mitchell LLP (QQ 247–259)
Dr Marcus Jepson, University of Bristol
JF
JM
Laura Jolley
- ** Professor Richard Jones, Cardiff Law School (QQ 25–44)
JT
The Judith Trust
KA
Kent and Medway MCA Local Implementation Network
- ** Kirsty Keywood, University of Manchester (QQ 25–44)
KG
Institute of Psychiatry, Kings College London
Professor Celia Kitzinger, University of York
Professor Jenny Kitzinger, Cardiff University
Liana Kotze
- * Norman Lamb MP, Minister of State for Care and Support,
Department of Health (QQ 312–333)
Lancashire County Council DoLS Team
Joan Langan, University of Bristol
- * The Law Society (QQ 25–44)
The Law Society of Scotland
Alix Lewer
- * Liberty (QQ 25–44)
Dr Liz Lloyd, University of Bristol
Michael Loftus
- ** Julia Lomas, Irwin Mitchell LLP (QQ 247–259)
London Borough of Bromley
London Borough of Hammersmith & Fulham
London Borough of Newham Adults Social Care
London MCA/ DoLS Network

- Dr Stephen J. Louw
Aisha Lowry
- * Senior Judge Denzil Lush, Senior Judge of the Court of Protection (QQ 292–311)
Luton Borough Council
- * Nicola Mackintosh (QQ 25–44)
Mira Makar MA FCA
MCA and MCA DoLs’ Team of Cambridgeshire County Council
John McKendrick
- * Lord McNally, Minister of State for Justice, Ministry of Justice (QQ 312–333)
Dr Julie McVey, University of Liverpool
Susie Meehan
- * Mencap (QQ 74–89)
Mental Disability Advocacy Center (MDAC)
Mental Health Alliance
- * Mental Health Foundation (QQ 45–55)
MHA & MCA Law
Sophy Miles
- * Mind (QQ 90–105)
- * Ministry of Justice (QQ 1–24)
MM
Tussie Myerson
- * Michael Mylonas QC, Serjeants’ Inn Chambers QC (QQ 247–259)
- ** National Autistic Society (QQ 74–89)
- * National Care Association (QQ 236–246)
- ** National Family Carer Network (QQ 126–138)
National University of Ireland, Galway
- * Mark Neary (QQ 260–269)
- * NHS England (QQ 221–235)
NHS Health Education England
Niamh (Northern Ireland Association for Mental Health)
Cher Nicholson, Monash University
North East London NHS Trust
North Staffordshire Combined Healthcare NHS Trust
North Yorkshire County Council
Northumberland, Tyne and Wear NHS Foundation Trust

Nuffield Council on Bioethics

Mary O'Toole

* Office of the Public Guardian (QQ 281–291)

* Official Solicitor to the Senior Courts (QQ 270–280)

Faculty of Health and Social Care, Open University

Sophia Palmer

Parliamentary and Health Service Ombudsman

Dr Demi Patsios, University of Bristol

PD

Professor Elizabeth Peel, University of Worcester

Pembrokeshire People First

PJ Care

* POhWER (QQ 106–125)

Marie Poole

David Rees

REF

Dr Claud Regnard FRCP

Rehabilitation Education and Community Homes Limited

Rescare (The Society for Children and Adults with Learning Disabilities and their Families)

Steven Richards

Professor Louise Robinson

** Alex Rook, Irwin Mitchell LLP (QQ 247–259)

Rotherham Doncaster and South Humber NHS Foundation Trust

Royal Borough of Greenwich, Best Interests Assessors Forum

* Royal College of General Practitioners (QQ 153–171)

Royal College of Nursing

* Royal College of Psychiatrists (QQ 153–171)

Royal Hospital for Neuro-disability

* Alex Ruck Keene, 39 Essex Street Chambers (QQ 247–259)

Safeguarding Essex

Jo Samanta, De Montfort University, Leicester

Paula Scully

SEAP

* Sense (QQ 45–55)

* Serjeants' Inn Chambers (QQ 247–259)

Sheffield Safeguarding Adults Board

- * Shropshire Council evidence (QQ 172–184)
Sam Smith
- * Social Care Institute for Excellence (SCIE) (QQ 185–196)
Society of Trust and Estate Practitioners (STEP)
Solicitors for the Elderly
Dr Oluwatoyin Sorinmade MSc (Psychiatry) MRCPsych LLM
- * South Essex Partnership University NHS Foundation Trust (SEPT) (QQ 260–269)
South West IMCA Group
St Helen’s Council
St Mary’s House
Standing Commission of Carers
Michael Stanley
John Stockley
Sussex Partnership NHS Foundation Trust
Polly Sweeney
Dr Paul Swift
Together for Mental Wellbeing
Richard Tucker
Rachel Turner
VPM
Elizabeth Verdonkschot
- * VoiceAbility (QQ 106–125)
Linda Ward, University of Bristol
Stephen Ward
Warrington and Halton Hospitals NHS Foundation Trust
Adrian Watts
West Midlands Regional DoLs Leads Group
West Sussex County Council
John White
Wigan Family Welfare
Professor John Williams, Aberystwyth University
Dr Val Williams, University of Bristol
WIRED
Worcestershire County Council and Worcestershire Health and Care
Trust integrated Learning Disability Teams
Dr Roger Worthington

APPENDIX 3: CALL FOR EVIDENCE

Select Committee on the Mental Capacity Act 2005

Call for Evidence

The House of Lords has established a Select Committee on the Mental Capacity Act 2005. The terms of reference of the inquiry ask the Committee to “consider and report on the Mental Capacity Act 2005”. The Committee will explore the following key issues in detail and would welcome your views on any or all of the following questions. Please note that questions are not listed here in any particular order of importance.

Written evidence should arrive no later than 2 September 2013.

Overview and context

- (1) To what extent has the Mental Capacity Act 2005 (MCA) achieved its aims?
- (2) Which areas of the Act, if any, require amendment; and how?
- (3) At the core of the MCA are its principles and definitions of capacity and best interests. Are these appropriate?

Implementation

- (4) To what extent have the five principles of the MCA been implemented in frontline practice? What evidence is available to assess this? Is there a satisfactory balance between enablement and protection?
- (5) How effective was the Government’s implementation plan? What measures were taken to ensure that professionals and families of those who lack capacity know about and act in accordance with the provisions of the MCA? Has it led to sustainable change?
- (6) Is the Act widely known and understood by professionals required to implement it? How does this differ across different sectors, such as health, social care, banking and others?
- (7) Is the Act widely known and understood by those who are directly affected by it and by their non-professional carers? To what extent does the Act provide protection and reassurance for informal carers? Has the right balance been struck between protection of the carer and protection of the individual lacking capacity?
- (8) Has the Act ushered in the expected, or any, change in the culture of care?
- (9) Is there any evidence that the provisions of the MCA affect some groups disproportionately? If so, what data exists to compare representation across different socio-economic groups, Black and Minority Ethnic groups, and gender?

Decision making

- (10) Are those directly affected by the Act being enabled and supported to make decisions for themselves to a greater or lesser extent than they would have been in the past? Does the means by which the decision is made—‘general authority’, Lasting Power of Attorney, deputyship, Court of Protection—affect the quality of decision making?
- (11) What evidence is there that advance decisions to refuse treatment are being made and followed?
- (12) Has the MCA fostered appropriate involvement of carers and families in decision-making?
- (13) Has the role of the Independent Mental Capacity Advocate (IMCA) succeeded in providing a voice for clients and an additional safeguard against abuse and exploitation for those who have no-one to speak on their behalf?
- (14) Has the level of referrals to IMCAs met expectations? What are the reasons for the regional variations in the number of referrals?
- (15) Are IMCAs adequately resourced and skilled to assist in supported or substituted decision making for people lacking capacity?

Deprivation of Liberty Safeguards

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

The Court of Protection and the Office of the Public Guardian

- (18) Are the Court of Protection and the Office of the Public Guardian sufficiently understood and accessible to all? Are they operating effectively and successfully?
- (19) What has been the impact of the introduction of Lasting Powers of Attorney (LPA), especially with regard to decision making on matters of personal care and welfare?
- (20) What concerns, if any, are there regarding the costs associated with registering an LPA, or with making an application to the Court of Protection?
- (21) Is legal aid available and sufficient? What impact will the recent and proposed reforms to legal aid have?

Regulation

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

Other legislation

- (24) How well is the relationship with the mental health system and legislation understood in practice?

Devolved administrations and international context

- (25) Does the implementation of the Mental Capacity Act differ significantly in Wales?
- (26) What lessons, if any, can be learnt from the approaches taken to mental capacity legislation in Scotland and Northern Ireland, or in other jurisdictions?
- (27) Is the MCA compliant with the United Nations Convention on the Rights of Persons with Disability (CRPD)? Are there lessons that can be learnt from the CRPD for the successful implementation of the MCA?

26 June 2013

APPENDIX 4: LETTER FROM NORMAN LAMB MP-6 NOVEMBER 2013

I write to inform you of the details of a new steering group my Department has established on the Mental Capacity Act 2005. The work of the steering group will include consideration of Deprivation of Liberty Safeguards.

In the Department's written evidence to your Committee in September 2013, we expressed the Government's belief that although the implementation programme put in place following the enactment of the Mental Capacity Act led to important steps forward in changing cultures to embed the Act, practice everywhere in the country does not fully meet the ambitions and expectations of the Act. As such, our intention is to work with national partners to assess progress in implementing the Act and decide what further action is required.

Furthermore, in the Government's response of October 2013 to the report of the Health Committee of the House of Commons on its post legislative scrutiny of the Mental Health Act 2007, the Department stated its intention to set up a new Mental Capacity Act Steering Group to inform our work in this area.

I am pleased to inform you that this Group held its first meeting on 14 October 2013. For your information, I enclose a copy of the Group's Terms of Reference, and details of its membership.

The ultimate purpose of the Mental Capacity Act Steering Group is "to agree a joint programme of action to continue to implement the Mental Capacity Act and the Deprivation of Liberty Safeguards". The Group is time-limited to 12 months in the first instance, after which members will decide whether it should continue to meet or its work be absorbed into existing programmes.

The insights and recommendations of your Committee will be vital in informing the Government's continuing work on the Mental Capacity Act and Deprivation of Liberty Safeguards. Please accept my thanks in advance for the invaluable work you are conducting in this area. If the Department can be of any assistance to your enquiries please do not hesitate to get in touch.

Norman Lamb MP

Mental Capacity Act Steering Group (MCA-SG)

Terms of Reference

Context

The Mental Capacity Act 2005 is a very significant piece of empowering legislation which affects some two million people and places responsibilities on people working in health and care settings to assess the capacity of people to make decisions, help them to make those decisions and, if they lack capacity, to take decisions for them in their best interests.

A number of national bodies are responsible for ensuring that the Mental Capacity Act and Deprivation of Liberty Safeguards are embedded in the work of the health and care sectors. Implementing the Mental Capacity Act and Deprivation of Liberty Safeguards are dependent on close, collaborative working between national bodies that are responsible for providing, commissioning, regulating, inspecting and overseeing health and care services and training and educating health and care staff.

This steering group brings together the key national bodies responsible for implementing the Mental Capacity Act and Deprivation of Liberty Safeguards.

Purpose

The ultimate purpose of the MCA-SG is to agree a joint programme of action to continue to implement the Mental Capacity Act and the Deprivation of Liberty Safeguards.

To achieve this purpose the MCA-SG will:

- (1) Discuss the evidence and share experience to reach a common view on the current state of implementation across the health and care sectors;
- (2) Decide how to promote understanding of the Mental Capacity Act and the Deprivation of Liberty Safeguards and to share best practice; and •
- (3) Take into account key legal developments or implementation issues . which have implications for the way in which the Mental Capacity Act and Deprivation of Liberty Safeguards are applied in the health and care sectors.

Management

The MCA-SG will be managed as a sub group of the DH Mental Health System Board.

The MCA-SG will be a time limited group operating for twelve months, after which time its membership will decide whether it should continue to meet or its work should be absorbed into the work of the Mental Health System Board.

It will meet quarterly.

Representatives will work together outside the quarterly meetings as necessary, to progress actions agreed by the Group.

Member organisations

The MCA-SG will include senior representatives from:

- Department of Health (Chair-Director of Social Care Policy)
- Ministry of Justice
- Office of the Public Guardian
- Court of Protection
- NHS England
- Care Quality Commission
- Local Government Association
- Association of Directors of Adult Social Services
- Health Education England
- Royal College of Psychiatrists
- NHS Confederation
- College of Social Work

- Social Care Institute for Excellence
- Public Health England
- Monitor
- East of England Strategic Clinical Network for Mental Health, Neurology and Disability
- Care Provider Alliance

Links to other boards

The MCA-SG will report to the Mental Health System Board on its discussions and, as appropriate, will raise any key issues to the Board for discussion. It will also update the Learning Disability Programme Board and Dementia Programme Board on its work.

APPENDIX 5: LETTER FROM NORMAN LAMB MP-28 NOVEMBER 2013

Thank you for your letter dated 12 November.

I am pleased that you view the establishment of the Mental Capacity Act Steering Group as a welcome development. The Group is very much concerned with trying to establish the evidence of the implementation of the Mental Capacity Act to date and arriving at a plan for improving the situation.

I absolutely agree with you that hearing from service users, families and carers should be at the centre of our efforts to understand the impact of the Act. I have asked officials to set up one or more events to ensure that we talk to a range of people who have direct experience of whether or not the Act is being used successfully. That evidence will be used to influence the work programme of the Steering Group and any subsequent action plan. We will ensure that this is not a one-off exercise but that we continue to consult and engage going forward.

The first meeting of the Steering Group was devoted largely to agreeing the terms of reference and clarifying the role of all the different organisations in implementation. The Group began to identify the areas of concern and gaps in our knowledge. Members were asked to identify what data we need for our analysis, what is available and from what source and what gaps there are and how we might remedy that. This topic will be the main focus of the next meeting arranged for January.

I look forward to meeting the Committee on 3 December.

Norman Lamb MP

APPENDIX 6: LETTER FROM NORMAN LAMB MP-9 DECEMBER 2013

On Tuesday I undertook to send you and the Committee a note on my views about whether I thought we had filled the “Bournewood gap” with the Deprivation of Liberty Safeguards (DoLS).

The “Bournewood gap” arose from a case where a patient lacked the capacity to consent to being kept at a hospital for assessment and treatment. The European Court of Human Rights found this was an unlawful deprivation of liberty that breached the requirement in Article 5(1) of the European Convention of Human Rights that a person can only be deprived of their liberty, without their consent, in accordance with a prescribed legal procedure. There had also been a contravention of the requirement in article 5(4) that any person deprived of their liberty should be entitled to take proceedings by which the lawfulness of the detention can be decided speedily by a court.

Consequently, the “Bournewood gap” was closed by the introduction of the DoLS in the Mental Capacity Act 2005 (MCA) by the Mental Health Act 2007. The DoLS ensure there is a legal procedure for authorising deprivations of liberty in hospitals and care homes for adults who lack capacity to consent to admission or treatment. DoLS is the framework of procedural safeguards comprising:

- section 4A: a person may be deprived of their liberty under the MCA if this is authorised by an order of the Court of Protection or a DoL authorisation under Schedule A1;
- Schedule A1: the qualifying requirements and process for DoL authorisations to be put in place, and subsequently reviewed; and
- Schedule 1A: the circumstances where the MCA (whether by an order of the Court of Protection or a DoL authorisation) cannot be used to deprive a person of their liberty.

The DoLS were designed to address the “Bournewood gap”, not just in hospitals, but also in care homes. The Court of Protection is also able to make a welfare order under the MCA to authorise a deprivation of liberty of a person in other settings (if they are not ineligible under Schedule 1A), and can determine the lawfulness of any deprivation of liberty under the MCA.

While the gap has been addressed by the legislation, there remain issues of awareness and appropriate use of the DoLS, and I accept that not all care homes and hospitals understand fully when the DoLS should be used. Further work is needed in this area.

An additional issue raised with you was whether there is ‘a gap’ in relation to possible deprivation of liberty in supported living accommodation. My view is that there is no gap as an application can be made to the Court of Protection to authorise a deprivation of liberty in supported living. We may revisit this in the future, as I said in evidence, as more people with complex needs are cared for in the community. For the moment I am content that local authorities should seek authorisation from the Court of Protection.

Lastly, in cases where a patient has been deprived of their liberty under the Mental Health Act, and medical treatment is required for physical conditions which are not related to the mental disorder, such treatment can be provided under section 5 of the MCA if the patient does not have capacity to consent to the treatment. In a very small number of cases, the treatment required may involve a deprivation of

liberty and in such cases the MCA regime is not available because the person is ineligible to be deprived of their liberty under Schedule 1A. However, the High Court has an inherent jurisdiction to authorise a deprivation of liberty for that purpose and therefore there is no gap which requires filling (and in any event, this is not the “gap” that was at issue in the Bournewood case).

You have also asked me to address question 8: The difficulty between providing the appropriate balance between safeguarding and protection has been a consistent theme in the evidence that we have heard. Given the understandable focus on safety within health and social services, how does the Government intend to prevent the empowering ethos of the MCA from continually being overshadowed?

I am very clear that the MCA is very much about the balance of protection and empowerment, and I think all the training and awareness raising and guidance makes this clear. The training invariably starts with the empowering principles—that people are assumed to have capacity; that people can have capacity about some matters and not about others; and importantly that a person must be helped to make a decision before they are found to lack capacity to do so. These are all very important and empowering principles.

As you heard from other witnesses, safeguarding has a longer history and is better established in health and social care. More people understand that their role involves making a safeguarding alert if they are worried about a person, and that there are safeguarding leads who will investigate safeguarding concerns.

We need to ensure that the empowerment message is equally understood. We do this through the guidance we produce; through the messages we give when speaking at conferences, and also through our wider policies on personalisation and choice and control. The empowerment message underpins the response to Winterbourne View; and much of what we are doing to enable people with disabilities to live in the community. It underpins our policies on ‘choice and control’ in both social care and the NHS. We will be writing safeguarding guidance to accompany the safeguarding clauses in the Care Bill, and we will ensure that this balance is present throughout the guidance.

I hope this information is helpful to you and the Committee.

Norman Lamb MP

APPENDIX 7: LETTER FROM LORD MCNALLY-10 DECEMBER 2013

Ministerial evidence session-3 December 2013

During the joint evidence session with Norman Lamb MP, I offered to write to the Committee on a number of matters on which the Committee sought further clarification.

The matters in question were the mediation pilot being undertaken by the Office of the Public Guardian (OPG) and the nature of the offences that had been prosecuted under section 44 of the Mental Capacity Act (MCA) 2005 and the Fraud Act 2006. I will deal with each in turn.

Mediation pilot

The pilot will allow the OPG to determine whether an in-house mediation service is a feasible option. The tender for the selection of the external partner who will assist the OPG in setting up a pilot scheme began in the late summer with the final selection taking place on 26 September, when Browne Jacobson solicitors in Nottingham were selected.

Cases where mediation may be particularly useful are those involving disagreement between family members of 'P' (the person lacking capacity), usually involving one or more attorneys of a Lasting Power of Attorney, (LPA), or a Court appointed Deputy over a decision required for P's best interests. The cases selected for inclusion in the pilot are likely to focus on the property and affairs issues in dispute between family members of P, though they may also include issues of health and welfare decision making, or a mixture of both.

The pilot will cover 15 to 20 cases which have been recommended by the Public Guardian (PG) as suitable for mediation. The mediation will be free to participants and it is hoped that they will be commenced in mid-January 2014, subject to the consent and availability of the involved parties. Mediation will take place via the telephone. Successful mediation will be particularly useful in cases where an attorney has been appointed as this will preserve the donors' choice of attorney.

Browne Jacobson will report to the Public Guardian by April 2014 with recommendations.

Nature of offences under section 44 of the MCA and the Fraud Act 2006.

Unfortunately whilst my department is able to provide statistics of the numbers of people who have been convicted under section 44 of the MCA and under the Fraud Act, we do not hold details of the exact nature of the offences. My officials have liaised with the Crown Prosecution Service. They do not hold details of the nature of the offences either and to obtain the information would require them to manually search through the case files.

However, from evidence recently collated from media articles by my officials, it would appear that the offence in the MCA is indeed being used to prosecute those who have the care of the person lacking capacity and that the Fraud Act is being used to prosecute where attorneys and deputies have abused their position and misappropriated funds.

Clearly there is work to be done to ensure that more use is made of the offence in the MCA and my officials will further discuss the matter with the CPS and will also contact the Association of Chief Police Officers.

You have also asked me to address question 8:

The difficulty between providing the appropriate balance between safeguarding and protection has been a consistent theme in the evidence that we have heard. Given the understandable focus on safety within health and social services, how does the Government intend to prevent the empowering ethos of the MCA from being continually overshadowed?

My colleague Norman Lamb MP has provided a substantive answer to this question but I would add that we are aware of the need to ensure that the empowerment message is understood, and my officials will continue to work with officials at the Department of Health to see how this can be achieved.

I look forward to reading the Committee's recommendations in due course.

Tom McNally

APPENDIX 8: MEMORANDUM FROM MINISTRY OF JUSTICE-12 FEBRUARY 2014

Memorandum from Ministry of Justice to House of Lords Committee on the Mental Capacity Act following oral evidence session with Lord McNally; Minister of State for Justice, Ministry of Justice and Norman Lamb MP; Minister of State for Care and Support, Department of Health on 3rd December 2013.

MoJ Response to the Committees request for clarification on changes to legal aid for people detained under the Mental Capacity Act following a press notice about changes to legal aid for people detained under the Mental Capacity Act— 8 January 2014.

“The article in the Law Gazette on 2 December is factually incorrect.

As Lord McNally made clear in Committee, when making the regulations under Part 1 of the Legal Aid, Sentencing and Punishment of Offenders Act 2012 (LASPO) the Ministry of Justice (MoJ) clarified that non means tested legally aided representation should be available to enable a person to challenge an authorisation to detain them made under Schedule A1 of the Mental Capacity Act 2005.

The purpose of this clarification was to put beyond doubt that means free funding was only to apply where an authorisation was in force and was the subject of a challenge under section 21A of the Mental Capacity Act 2005.

The MoJ gave evidence clarifying this policy in the Court of Protection case to which the article refers, and we are still awaiting a final judgment. Contrary to what is said in the article, the MoJ did not concede that the change to the regulations was unlawful, nor did we undertake to reverse it. We will of course consider carefully anything that the court has to say on the point in its judgment when that is received.”

APPENDIX 9: REPORT OF A SPECIAL MEETING OF THE FORGET-ME-NOTS

This special meeting was held to discuss the impact that the Mental Capacity Act has had on members of the group.

The meeting was held at the request of the Dementia Engagement and Empowerment Project (DEEP). DEEP had been approached by the House of Lords Select Committee on the Mental Capacity Act 2005 to find out the experiences of people with dementia.

This report will be submitted as written evidence to the House of Lords Select Committee.

About The Forget-Me-Nots

The Forget-Me-Nots are a group of people with dementia from the area of East Kent, who meet regularly in Canterbury. The group aims to help people with dementia get their voices heard. It is supported by the local NHS Trust, and co-chaired by Reinhard Guss, Consultant Clinical Psychologist, Elisabeth Field, Clinical Psychologist, Mental Health Services for Older People and Keith Oliver who has dementia and is Kent and Medway Primary Trust Dementia Service User Envoy.

The group aims to help organisations, including the local NHS Trust to improve the quality of service they offer to people with dementia. The group believes it is vital that the opinions of people living with a diagnosis are heard by those who make decisions. The group also functions as a network, where people can meet others with a similar diagnosis and get to know them better.

The Forget-Me-Nots is a key group within the Dementia Engagement and Empowerment Project (DEEP). DEEP provides support to existing and new 'involvement' or 'influencing' groups of people with dementia across the UK. The project is being developed in collaboration with people with dementia, and includes opportunities for sharing resources and ideas, building the capacity of groups, setting up networking opportunities between groups, supporting existing groups to mentor emerging groups and, in time, for groups to form a national network of collective voices.

About the meeting

Nine members of the Forget-Me-Nots attended the meeting.

Nada Savitch from Innovations in Dementia and DEEP chaired the meeting. We split into two groups to discuss issues around the Mental Capacity Act—these groups were facilitated by Nada Savitch and Reinhard Guss.

Lord Hardie and Lord Swinfen along with Judith Brooke (clerk to the Committee) kindly attended the meeting to listen to the views of people with dementia.

Five students helped the meeting run smoothly and took notes. We discussed such issues as:

- Who makes decisions in your life? Are there decisions which you make for yourself? Are there decisions which are made by others on your behalf?
- If someone has helped you to make decisions or made a decision for you ... What happened? What did it feel like?

- Have you had any experience of someone assessing your ‘mental capacity’?
- Have you had experiences of Lasting Power of Attorney?
- Have you had experiences of telling your bank or other organisations that you have dementia?

What members of The Forget-Me-Nots said

This report summaries what was said at the meeting across the two groups.

Direct quotes are used but (for privacy) they are not attributed to named members of the group.

The conversations did not necessarily happen in the order set out below.

About making decisions

The group all agreed that they all have the capacity to make decisions, but that this is slowly changing. And other people might be making more decisions on their behalf.

“It’s like the door is slowly shutting”

“It moves more to my wife now than me”

“My wife tells me what to wear ... she didn’t do that before I got dementia”

Some members feel they are still able make the same decisions. Others feel less confident.

“I was the main decision-maker ... but now my wife can think it out better than I can”

“I still make decisions; they just might not be the right ones” “I don’t have confidence in my decisions”

“Everything’s just the same, except I can’t think some things out now”

Some members found this change in decision making difficult as it means they are losing independence.

“My wife has made decisions for me ... it doesn’t feel good. I want to make decisions”

Some members thought sometimes decisions were made about them for the right reasons.

“I want to be protected as I become more fragile, less able to make decisions”

“In my world I’m not different [to how I was before dementia]—I think I’m still alright”

“It’s easier to take if you can see that the decision is being made for your own benefit”

People felt that it is important that information is presented in a way that is easy to understand.

Telling officials that you have dementia

Members of the group felt that they had been treated differently when they had told people they had dementia.

Sometimes this was for the better—one member had been in Lloyd’s bank (which is working with Alzheimer’s Society) and had had a helpful response. Others had good experiences too.

“We have a great relationship with the bank and they help us a lot, we always see the same person”

Others felt they were patronised and discriminated against for having dementia, or just being older.

People had different thoughts about the needs or desirability of telling officials about their diagnosis.

“I don’t mind telling people, I just don’t think it’s necessary yet” “I wouldn’t tell the bank until I was really downhill”

“I don’t mind telling people, I just don’t want sympathy”

“With utilities, if they don’t know you have dementia, how can they help you?”

There was a suggestion that details of lasting power of attorney could be added to Alzheimer’s Society ‘I have dementia’ cards.

Being assessed for capacity and best interest

People felt some apprehension about being assessed for mental capacity. They felt it fluctuated and was especially dependant on whether you were feeling anxious or depressed at the time.

“It makes me nervous”

Some people did feel that people were judging their mental capacity.

“I feel I might be prejudged if I’ve told someone I have dementia” The concept of ‘best interest’ is a difficult one, and many people are not aware of it.

“Best interest ... that’s difficult to define”

Bad experiences of Mental Capacity Act

Some members of the group referred to friends and relatives who had bad experiences under the Act.

There was particular concern about cases where there was no Lasting Power of Attorney and people had to work through a solicitor.

“The wife can’t access the money—she can’t get the money out without going to the solicitor”

“It costs £5000 a year”

“Why can’t the carer go back and get the power of attorney?” “Is there a standard fee?”

“Do you have a choice of solicitors?”

There was a feeling that that Act does not always support those it says it is there to protect. And that the balance between protecting people and stopping the minority that may exploit people with dementia was sometimes wrong.

“The Act seems to be working against the innocent rather than protecting them”

“How can we deal with this unscrupulous minority without inhibiting the scrupulous?”

“Are people judged not to have capacity too soon?” “The Act focusses too much on exploitation”

Lasting Power of Attorney

Lasting Power of Attorney was one aspect of the Mental Capacity Act that was familiar to most people at the meeting, although many people did not have one, and some people were not clear about what was covered.

“Is the idea that it’s just financial?”

“Older people might think it’s not for them”

“It might be more important for someone with young onset dementia, less so for someone in their 80s—we don’t really mind what happens to our money”

Most people agreed that it was a very good idea and should be done early on.

“Make your wishes know now!”

“It’s important to write things down” “Do it early and put it on one side”

Many people felt that the process was complicated and difficult to understand.

“It’s difficult, it feels like going up a mountain” “It takes a lot of thought—it’s lengthy”

“It took me three months to get to grips with it”

“The big pile of paper needs to be reduced”

In many people’s experience it was an expensive process that needed a solicitor.

“You need advice from a solicitor”

“I drew it up myself and got a lawyer to sort it for me” “It cost me about £1000”

“A list of approved solicitors would be good”

There was a feeling that although it’s a good thing to do, people put it off or don’t get round to it.

“It’s too difficult—it puts people off” “It’s expensive and daunting”

“There needs to be more encouragement for people to do it—we tend to park it”

“It’s not just us who put it off, it becomes a taboo subject—family members don’t want to talk about it either”

“We like to live for the day—we don’t want to discuss this all the time”

There is confusion about how power of attorney operates with utilities and banks.

“Even if the attorney goes to the bank or the utilities, they don’t know that the power of attorney has been given”

“The utilities will only speak to the person whose name is on the account—they won’t take the spouses word for the fact that they have power of attorney”

People felt that organisations such as banks and utilities should have access to information about who holds power of attorney.

“Utilities should have access to that information”

“They should create a register where you can check who has power of attorney”

Some people felt that power of attorney should be an automatic right within marriage or part of the marriage vows. But others felt that there were complications due to divorce and people living together.

“In case of marriage, shouldn’t be assumed?”

It was agreed that it can sometimes be difficult to find someone to take on the attorney role.

“Decisions should be made by someone you trust”

“It’s hard to find people you trust enough or who want to do it” “I don’t want to burden my children”

People felt that couples should make Lasting Power of Attorneys together.

Information about the Mental Capacity Act

There was also a feeling that there is too little information available about the Mental Capacity Act and Lasting Power of Attorney in particular.

“There’s not enough information about it generally” “200,000 people need this information”

“Lots of people with dementia are older—how do they know about it?”

“Why does everything have to be online?” “There needs to be more advertising”

“We had a lawyer turn up to our post-diagnostic support group to explain”

“It’s important to be informed by someone you trust”

But people agreed that at diagnosis there is often an overload of information.

The voluntary sector, especially CAB and Alzheimer’s Society were thought to have a role. [The Alzheimer’s Society does have a good information sheet about the Act]

“The Alzheimer’s Society could have a role in informing people about the Act”

“Banks and CAB etc should be there to help you fill in the forms”

Language

Some people didn’t like the term ‘Mental Capacity Act’ because of the association with mental illness.

It was felt that labels such as ‘carer’ and ‘sufferer’ can foster stereotypes

“We still care for our partners even when we have dementia”.

Canterbury, 30 October 2013

APPENDIX 10: NOTE OF THE COMMITTEE VISIT TO THE COURT OF PROTECTION-20 NOVEMBER 2013

Note by the Clerk and Policy Analyst

Overview of the Visit

A delegation of the Committee visited the Court of Protection on Wednesday 20 November 2013. The members of the delegation were Lord Hardie (Chairman), Lord Alderdice, Baroness Barker and Baroness Hollins. They were accompanied by the Specialist Adviser, the Policy Analyst and the Clerk.

The purpose of the visit was to provide members with the opportunity to view proceedings. However, at the suggestion of the Vice-President of the Court of Protection, Mr Justice Charles, the visit also included a tour of the so-called 'back office' functions of the Court. Having viewed the proceedings and toured the offices, the delegation subsequently met with Mr Justice Charles, a number of high court judges and district judges, and staff of the Court of Protection and the Family Division for a brief Question & Answer session. Staff included 'authorised officers', a role introduced in 2011 to adjudicate in non-contentious property and affairs cases. This note summarises the main points raised over the course of the tour, the proceedings and Question & Answer session.

'Back office functions'

The staff of the Court were keen to emphasise that the vast majority of the work of the Court takes place outside the court room, in the routine administration of applications concerning property and affairs (around 95% of the caseload). Of those applications 93% were non-contentious, according to figures provided by Mr Justice Charles. These were cases which were decided on the papers, without recourse to a hearing, by a small group of authorised staff in a quasi-judicial function.

The volume of applications to the Court of Protection could reach upwards of 100 per day. The majority of these concerned property and affairs, although welfare applications were dealt with as well. How to manage such volumes in a timely manner was of great concern to the management and staff of the Court. Processes were monitored and timed precisely: a wall chart in the corridor showed that the target time for conducting a basic check on a COP44A application form, including whether the form had been completed, signed and dated, was 4.4 seconds. A member of staff commented that the office's move to open plan accommodation would reduce time lost moving between offices, and passing through time-consuming security doors.

There are four 'authorised officers'. Their role in adjudicating on non-controversial property and affairs cases was introduced in 2011, following the report by the Rules Committee. Enabling non-judicial staff to complete the routine administration of such matters was designed to remove the backlog of cases, which had grown to 3000. They considered 200 cases a manageable workload and work towards the key performance indicators (reply to initial application within 20 working days in 95% of cases; decision where there is no oral hearing within 16 weeks in 75% of cases). However, they admitted that their small number created a pinch point in the process. When necessary, and provided other

demands on their judicial time allowed it, the four District Judges were able to provide help.

Urgent applications were dealt with by a dedicated office. The aim was to deal with the form within one hour and then to contact a judge for an immediate hearing. The office operated 9-5, five days a week, but there was 24 hour out-of-hours access through the Royal Courts of Justice. There was a dedicated route for making urgent applications that ensured they come into the correct office, but this was not always followed. One example of the changes planned for application forms was to allow applicants to indicate on the front of the form if it was urgent. Examples given of urgent cases were an application by a local authority on the legality of preventing a young woman with learning disabilities from going to a party, where there was a legitimate fear that she would be sexually exploited, and a woman who had barricaded herself into her home against a bailiff with a warrant to seize property. In the latter case the Court was able to contact the bailiff directly and request that they delay enforcement of the warrant while a property and affairs deputy was appointed, who subsequently applied for the warrant to be suspended due to the vulnerability of the individual concerned.

The office also provided a supervisory function for deputies and attorneys, handling applications for financial and property decisions outside the standard powers of a deputyship or LPA. The example was given of an application by an attorney to buy the dwelling house of P. It was acknowledged that this could be appropriate but that the Court would insist on safeguards, such as ensuring that the price paid for the home was not less than the market value. This could lead to delays while valuations were obtained but it was felt to be a necessary safeguard.

The office also contained a call service. When the delegation visited there appeared to be few calls being taken, but it was reported that the average was 500-700 calls per day. There were issues with the telephone system leading to problems receiving calls and when this occurred there was a resulting increase in e-mail enquiries, which had recently tripled. It was acknowledged that callers to the service were frequently vulnerable and required more assistance than most; there was therefore no restriction on the length of calls.

Proceedings

The delegation observed two different sets of proceedings.

The judge in the first set of proceedings was Mrs Justice King. The case was on day three of three and proceedings consisted of an application to accept further submissions, which was denied, and the issuing of the judgment. It concerned a personal welfare, residence and parental contact application regarding the third son of the family to be placed in residential care. The commissioner for health care wished the court to determine that P no longer met the criteria for NHS continuing health care funding and that this was the responsibility of the Local Authority. P resided in a care home for people with severe learning disabilities. He required 2 to 1 care during the day time, and 1 to 1 care at night. He had the cognitive capacity of a one year-old child. His parents disagreed with the placement and had expressed grievances about the care being provided. Placement of P was at risk as due to the dispute over the funding of P's care.

The parents had made several appeals and attempts to discharge the care orders made in this and the previous cases involving his brothers. Previous proceedings in respect of two older brothers of P had been litigated and the parents sought to re-open these cases. They made claims under Article 8 of the Human Rights Act.

P was represented in the case by the Official Solicitor who had engaged Counsel to act for P in Court. Both the health care commissioner and the family were also represented. P was not in Court, but his parents were present, as were the press. In giving the judgment Mrs Justice King indicated that she would use the names of P and his parents in giving the judgment, as a matter of respect for them, but that the printed judgment and all reporting of it should refer to them only by their initials. The judgment was read out in full, with approximately an hour allowed for this. The delegation were present for the first 20 minutes of the judgment, which illustrated some of the issues that the Committee had heard of, including: significant dispute between the family of P and service providers concerning standards of care; unsuccessful attempts at informal resolution, including through changes to the care and contact arrangements provided to P and his family; and cost as a factor in deciding on available care package options. The judgment was subsequently published online following anonymisation.

The second case the delegation observed was heard by Mr Justice Baker. It concerned an application to restrict the online activities of P on the basis that he had an addiction to pornography, a history of sexual offending and was likely to access child pornography. P was present but not legally represented. An interim order declaring that P lacked capacity was made, despite conflicting evidence on capacity. The local authority sought permission to disclose information regarding P to other agencies as part of public protection measures and this resulted in a request by Mr Justice Baker that the Official Solicitor give urgent attention to the appointment of a case manager so that the issue of disclosure could be heard swiftly.

Mr Justice Baker spoke to the delegation after the hearing and outlined some of the challenges presented by the second case, including whether the Court of Protection was the appropriate place to decide on questions of access to pornography. He went on to outline two further cases due to be heard that day, the first relating to accommodation for an individual whose care home was closing, and involved a dispute between her mother and the local authority; the second case related to care arrangements for the children of a person with a significant brain injury. The latter case raised issues with regard to the management of compensation funds and the response of the Court of Protection where issues outside its jurisdiction arose. In this instance Mr Justice Baker was able to act as both a Court of Protection judge and a Family Court judge and deal with both the MCA questions and the care proceedings. When questioned on the legal basis for this, it was explained that this was a pragmatic solution that was not infrequent and had not yet been challenged by parties.

Question & Answer session

The delegation met with Mr Justice Charles, a number of high court judges and district judges, and staff of the Court of Protection and the Family Division, including authorised officers, for a brief Question and Answer session.

The discussion covered the practice of reading out of judgments in full, which was reported to be a question of discretion and preference for individual judges. Some preferred to give a short summary of findings followed by a full judgment later on.

The call for a dedicated website and digital telephone line, made by staff during the tour of the office, was raised again during this session. The delegation was informed that the digital roll-out had been delayed by technical difficulties but was expected to reach the Court of Protection by April 2014. Regarding the website,

there was discussion as to the most appropriate way of ensuring that the technical information regarding the Court was made widely available and accessible. Staff felt it important that they were able to respond to issues of concern, for example by placing guidance on urgent applications in a prominent place. Frustration was expressed regarding the constraints on the material that could be presented through the www.gov.uk website and the lack of control that gave the Court. It was felt that a dedicated website could contribute significantly to addressing accessibility and remoteness of the Court.

It was reported that the number of applications relating to issues outside the remit of the Court had increased, particularly following cuts to legal aid. Staff attempted to direct such applicants to the appropriate service, but they were not experts so were often limited to advising the individual to contact the Citizen's Advice Bureau or similar. Applicants were generally clearer on which property and affairs issues needed Court oversight, but applications were sometimes made for a deputyship when an appointeeship by the Department for Work and Pensions would be more appropriate, as well as less restrictive and costly.

The desirability of increased mediation was discussed, with some participants in favour. Options included encouraging greater access to mediation provided through local authorities, although the suitability of this was questioned in cases of dispute with the local authority. It was pointed out that since the costs of litigation fall on P and P's estate, there was no incentive to mediate rather than litigate. One participant suggested that a potential solution would be for punitive costs to be attached to parties for failure to attempt mediation prior to litigation. Discussion also covered the potential for the Court to provide mediation, including as a pre-condition of application or active engagement in case management meetings. While some were in favour of this approach, all agreed that this would not be possible with current levels of resources. It was also acknowledged that current practice tried to encourage resolution between parties or, as a minimum, a 'narrowing of the issues' through agreement on all but the areas of significant contention.

The visit concluded with the Chair thanking all those present for their assistance to the Committee.

November 2013

APPENDIX 11: NOTE OF THE COMMITTEE VISIT TO MEET ADULTS WITH LEARNING DISABILITIES-28 NOVEMBER 2013

Note by the Clerk and Policy Analyst

Overview of the Visit

A delegation of the Committee met with a group of adults with learning disabilities convened by Mencap Hammersmith and Fulham branch on Thursday 28 November 2013. Among the group were members of Safety Net People First, a self advocacy group of adults with learning disabilities. Some participants were accompanied by carers or support workers to assist their communication. The members of the delegation were Lord Hardie (Chairman), Lord Faulks and Baroness Barker. They were accompanied by the Policy Analyst and the Clerk.

The purpose of the visit was to provide members with the opportunity to speak directly with adults with learning disabilities about their experiences of decision-making. It was held in the Council Chamber of Hammersmith and Fulham Town Hall. We are grateful to Hammersmith and Fulham Council for the use of their facilities.

Prior to the visit, Mencap held a preparatory meeting to ensure that participants felt able to contribute to the meeting. During the meeting with Committee members an easy-read presentation was used to help guide the discussion. The presentation can be found on our website.⁵⁶⁵ We are grateful to the staff of Mencap Hammersmith and Fulham branch for their support in arranging and facilitating the meeting.

Following introductions, the participants split into two groups, each facilitated by a member of staff from Mencap. Subsequently there was a break during which participants were able to speak individually with committee members. The visit closed with a final plenary session and words of thanks. This note summarises the main points which were raised over the course of the discussions.

Key themes emerging from the discussions

The right to make decisions, and the right to support to make and implement decisions

Many participants reported a strong desire to make their decisions and to be supported in making and implementing them. A mother with learning disabilities shared her experience of the removal of her first child by her parents and social workers. Her parents cared for her child and her daughter grew up believing she was her sister. She was not allowed to hold her due to fears that she would drop her. She had asked for help holding her, but it was not sufficient. She felt strongly that she should have been provided with support to bring up her daughter and that had such support been available she would have been able to parent her. She reported that she now has two sons, whom she is bringing up with the support of her brothers and sisters, and she now has a relationship with her daughter.

⁵⁶⁵ <http://www.parliament.uk/documents/Mental-Capacity-Act-2005/NoteoftheCommitteevisittoadultswithlearningdisabilities-webversion.pdf>.

Another participant said he liked to take holidays and was supported in order to do so. He would be shown pictures of places until he chose which one he wanted to visit. He would visit first for a couple of days and if he liked it, he would book a longer holiday. His carers would support him in doing this.

Another man reported that he liked to take holidays and had done so successfully on a number of occasions, including to Egypt and Australia, with the support of one carer whose travel he paid for. However, he wasn't always happy with the arrangements for deciding on and planning his trips. He reported that on one occasion his support workers had decided that his next holiday should be to New York and that he would need two support workers, despite the increased costs this would entail, and the fact that he had previously travelled with just one. He had not wanted to go to New York. He said that when he was there his support workers spent the whole time shopping and that he had developed blisters on his feet from being 'dragged around shops.'

Another participant described having to make 'a very hard decision' about whether or not to have an invasive treatment. She was supported in making the decision by her doctors. They explained in simple language the consequences of not having the treatment, and they gave her time to consider her decision. She consulted her mother who said it was up to her. She made her decision alone.

Not all participants were keen on making their own decisions. One woman said she did not want to make decisions alone, she preferred to have support. She said support was available from her key social worker but sometimes she was obliged to see other social workers. She would like to have support available 24/7 as she was worried about 'getting it wrong.' Another woman agreed; she liked to have her partner support her because she struggled to do things on her own.

The importance of being involved in decision-making when the person lacks capacity

Many of the participants were unhappy about not being involved, or not being sufficiently involved in decisions that affected them. The term 'behind my back' was used by several participants about decisions that had been made in their lives. Some participants were familiar with the term 'best interests.' One woman, for example, said she would like her mother and key social worker present at any best interests meeting to support her; she was concerned things would 'go wrong' if she went on her own.

One participant was unhappy following a recent move to a new property. She had appealed to the Council to move her again. They had refused. She had not been involved in the decision to move to the new property and she felt the Council were not acting in her best interests. She was challenging the decision with the help of an advocate.

Another participant reported that she wanted to stop taking her medications. She had been told 'no'. She did not feel involved in the decision.

Another woman was unhappy that her finances had been rearranged without her involvement. Her social worker was aware that she was having difficulty budgeting and had arranged for her bills to be paid directly by social services, and for her benefit money to be delivered in small amounts three times a week. Previously she had spent all her benefit money at once. She now found that she was able to budget throughout the week. She was happy with the outcome but she was unhappy not to have been consulted.

One participant had a more positive story. He had had to move care homes because his home was closing. He did not have the capacity to make the decision himself. Social workers took him to a number of possible homes until they found one that he liked. However, it still took a number of months before he was happy to move into his new home. In the meantime, he visited the home and had his photo taken there as part of a process of becoming more comfortable with the move.

One man wanted help to ‘plan his life’. He wanted a person-centred plan, made with support from others involved in his care. He wanted to be at the centre of his life. This particular participant spoke to members of the Committee individually after the group discussions. He was supported during the meeting by his mother and a care worker. His communication was through a Lightwriter SL35 with voice output—a keyboard which allowed him to type out responses to questions which were then vocalised electronically. The members were told how his parents supported him to take an active part in the decisions which affected him. He was involved in choosing his activities. He had also been able to vote on three occasions in the London Mayoral elections. His parents had helped to prepare him for this decision by making scrapbooks of each of the candidates, outlining their policies and what they stood for. They had provided the information clearly and in small bursts. The process had taken three months. Additional information submitted by his parents can be found on our website.⁵⁶⁶

Respect for choices by adults with learning disabilities

Respect for choices made by adults with learning disabilities was a recurring theme. One participant felt very strongly that there was a need for greater respect for the right of adults with learning disabilities to have relationships. It was later reported that she was in a relationship with one of the other participants, but both had felt unable to discuss this due to the presence of her partner’s carer, who disapproved of the relationship.

One man reported that he had been prevented by social services from buying gifts for the people that he lived with.

Another man gave the example of trying to book a holiday with his mother. He had been moved into residential care as a result of abuse by his mother. After his move his confidence and his relationship with his mother had improved. He decided he wanted to take her on holiday with him. Staff at the care home had supported him in understanding the decision, and he had shown he understood the cost involved by expressing this as being equivalent to ‘10 televisions’. Social services did not accept this and repeatedly asked the home for information to undertake a capacity assessment, rather than talking to him directly.

Experiences of discriminatory treatment

Several participants reported discriminatory, threatening or violent behaviour. One participant described a very difficult relationship with her parents, with whom she no longer lived. She reported trying to leave the family home, which felt like a prison to her, resulting in a beating with a belt. She felt she was not able to

⁵⁶⁶ <http://www.parliament.uk/documents/Mental-Capacity-Act-2005/NoteoftheCommitteevisittoadultswithlearningdisabilities-webversion.pdf>

challenge the treatment she received because it involved her parents; she felt it would have been different if they had been paid carers.

One woman talked about an example of violence from a neighbour. When she reported it the police had failed to take action because they did not believe her account and they had no other witnesses.

One participant said that she responded to being sad about being treated badly by writing and singing songs about her experiences. Another said that he 'takes it out on the drums', while yet another played the keyboard.

Post script to the visit

Following the visit, the facilitators from Mencap Hammersmith and Fulham branch provided additional information from the participants about the support they receive when making decisions. The things they liked about the support they received were:

- I am included to make decisions.
- I get to choose what I want to do
- My sister helps me
- I like having help with my money
- Have friends involved

Some things could have been done better:

- Talk to me first about it.
- Make sure family don't overrule me
- Check after decisions are made that I still feel the same way.

APPENDIX 12: GLOSSARY OF ACRONYMS

ABI	Acquired Brain Injury
ADASS	Association of Directors of Adult Social Services
ADRTs	Advance Decisions to Refuse Treatment
BASW	British Association of Social Workers
BIA	Best Interest Assessor
BIHR	British Institute of Human Rights
CCG	Clinical Commissioning Group
CIPOLD	Confidential Inquiry into premature deaths of people with learning disabilities
CQC	Care Quality Commission
DoLS	Deprivation of Liberty Safeguards
ECHR	European Convention on Human Rights
EWCA	England and Wales Court of Appeal
GMC	General Medical Council
GP	General Practitioner
HoL	House of Lords
IMCA	Independent Mental Capacity Advocate
KPI	Key Performance Indicator
LGO	Local Government Ombudsman
LLP	Limited Liability Partnership
LPA	Lasting Power of Attorney
MCA	Mental Capacity Act 2005
MDAC	Mental Disability Advocacy Center
MHA	Mental Health Act 1983 (amended by Mental Health Act 2007)
NHS	National Health Service
OPG	Office of the Public Guardian
P	Person under the Mental Capacity Act 2005
PCT	Primary Care Trust
PHSO	Parliamentary and Health Service Ombudsman
RC Nursing	The Royal College of Nursing
RPR	Relevant Person's Representative
SCIE	Social Care Institute for Excellence
UNCRPD	United Nation Convention on the Rights of Persons with Disabilities