



House of Lords  
House of Commons  
Joint Committee on  
Human Rights

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# **A Life Like Any Other? Human Rights of Adults with Learning Disabilities**

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**Seventh Report of Session 2007–08**

*Volume I*





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***Volume I***

*Report and formal minutes*

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## Joint Committee on Human Rights

The Joint Committee on Human Rights is appointed by the House of Lords and the House of Commons to consider matters relating to human rights in the United Kingdom (but excluding consideration of individual cases); proposals for remedial orders, draft remedial orders and remedial orders.

The Joint Committee has a maximum of six Members appointed by each House, of whom the quorum for any formal proceedings is two from each House.

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The Committee has the power to require the submission of written evidence and documents, to examine witnesses, to meet at any time (except when Parliament is prorogued or dissolved), to adjourn from place to place, to appoint specialist advisers, and to make Reports to both Houses. The Lords Committee has power to agree with the Commons in the appointment of a Chairman.

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The Reports and evidence of the Joint Committee are published by The Stationery Office by Order of the two Houses. All publications of the Committee (including press notices) are on the internet at [www.parliament.uk/commons/selcom/hrhome.htm](http://www.parliament.uk/commons/selcom/hrhome.htm).

### Current Staff

The current staff of the Committee are: Mark Egan (Commons Clerk), Bill Sinton (Lords Clerk), Murray Hunt (Legal Adviser), Angela Patrick and Joanne Sawyer (Committee Specialists), Jackie Recardo (Committee Assistant), Karen Barrett (Committee Secretary) and Jacqueline Baker (Senior Office Clerk).

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# Contents

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| <b>Report</b>                                                                                       | <i>Page</i> |
|-----------------------------------------------------------------------------------------------------|-------------|
| <b>Summary</b>                                                                                      | <b>5</b>    |
| <b>1 Introduction</b>                                                                               | <b>7</b>    |
| Our inquiry                                                                                         | 7           |
| Learning disabilities or learning difficulties?                                                     | 8           |
| Terms of reference                                                                                  | 9           |
| Evidence and visits                                                                                 | 9           |
| Structure of our report                                                                             | 10          |
| Specialist advisers and acknowledgements                                                            | 10          |
| <b>2 Adults with learning disabilities: the key issues</b>                                          | <b>11</b>   |
| Abuse and neglect                                                                                   | 11          |
| Failures in healthcare                                                                              | 13          |
| Victims of crime                                                                                    | 14          |
| Are people with learning disabilities especially vulnerable to infringements of their human rights? | 15          |
| The policy context                                                                                  | 17          |
| Where we are now: Are we valuing people?                                                            | 18          |
| <b>3 Why do human rights matter?</b>                                                                | <b>21</b>   |
| What does the Human Rights Act add?                                                                 | 21          |
| Disability, equality and human rights                                                               | 23          |
| UN Convention on the Rights of Persons with Disabilities                                            | 25          |
| Independent living and human rights                                                                 | 27          |
| <b>4 Living with a learning disability</b>                                                          | <b>29</b>   |
| Access to public and other services                                                                 | 30          |
| Access and choice in housing                                                                        | 31          |
| Access to paid employment                                                                           | 32          |
| Relationships with friends and family, sexual or other personal relationships                       | 32          |
| Participation in decision-making, speaking up and making complaints                                 | 33          |
| Participation in the local community                                                                | 34          |
| Families and carers                                                                                 | 34          |
| The gap between policy and practice                                                                 | 37          |
| Inability to access services and support                                                            | 39          |
| Is it all about the money?                                                                          | 40          |
| Negative attitudes, assumptions and stereotypes about people with a learning disability             | 43          |
| <b>5 The treatment of adults with learning disabilities in health and residential care settings</b> | <b>48</b>   |
| Abuse, neglect and careless treatment of adults with learning disabilities                          | 51          |
| Human rights in healthcare: A human rights based approach                                           | 53          |
| The role of the health and social care inspectorates                                                | 54          |

|                                                                                               |            |
|-----------------------------------------------------------------------------------------------|------------|
| Access to specialist, primary and acute healthcare services                                   | 55         |
| <b>6 Parenting and family life</b>                                                            | <b>58</b>  |
| Access to support for parents with learning disabilities and their children                   | 60         |
| Access to information for parents with learning disabilities                                  | 63         |
| <b>7 Treatment of people with learning disabilities in the criminal justice system</b>        | <b>66</b>  |
| Victims of Crime                                                                              | 66         |
| Taking crimes against people with learning disabilities seriously                             | 68         |
| Increasing the confidence of people with learning disabilities in the criminal justice system | 70         |
| Hate crimes and learning disability                                                           | 72         |
| Accused and defendants                                                                        | 74         |
| Prisoners                                                                                     | 75         |
| <b>8 Barriers to an 'ordinary life'</b>                                                       | <b>77</b>  |
| Access to information                                                                         | 77         |
| Accessible information on human rights                                                        | 80         |
| Access to independent advocacy                                                                | 82         |
| Voting rights                                                                                 | 87         |
| Support to participate in the local community                                                 | 89         |
| Role of service providers                                                                     | 92         |
| <b>9 Conclusions: Putting human rights principles into practice</b>                           | <b>94</b>  |
| The role of Government                                                                        | 95         |
| The role of the Equality and Human Rights Commission                                          | 96         |
| <b>Conclusions and recommendations</b>                                                        | <b>97</b>  |
| <b>Annex 1: Relevant human rights laws and standards</b>                                      | <b>112</b> |
| Common law principles                                                                         | 113        |
| Human Rights Act 1998                                                                         | 113        |
| Convention rights                                                                             | 113        |
| Right to life (Article 2)                                                                     | 113        |
| Freedom from torture or inhuman or degrading treatment or punishment (Article 3)              | 114        |
| Right to liberty (Article 5)                                                                  | 114        |
| Right to a fair hearing (Article 6)                                                           | 115        |
| Right to respect for private and family life, home and correspondence (Article 8)             | 115        |
| Prohibition on discrimination (Article 14)                                                    | 116        |
| Disability Discrimination Act 1995 (as amended)                                               | 116        |
| Disability Equality Duty and the promotion of equality of opportunity                         | 118        |
| The Mental Capacity Act 2005                                                                  | 118        |
| UN Convention on the Rights of Persons with Disabilities                                      | 119        |
| Themes arising from human rights standards and legislation                                    | 120        |
| Positive obligations to promote human rights and equality                                     | 120        |
| Equality and human rights – equality of opportunity                                           | 121        |

|                                                                            |            |
|----------------------------------------------------------------------------|------------|
| Promoting participation                                                    | 121        |
| Challenging negative assumptions, stigma and discrimination                | 122        |
| <b>Annex 2: Contributions to the inquiry from members of the public</b>    | <b>123</b> |
| Themes and concerns                                                        | 123        |
| A lack of understanding for people with learning disabilities              | 123        |
| Discrimination, bullying and abuse                                         | 124        |
| Access to funding for services and support                                 | 125        |
| The gap between the policies in Valuing People and reality on the ground   | 127        |
| Importance of advocacy and Easy Read information                           | 128        |
| Supported or independent living                                            | 128        |
| Human rights, education and training                                       | 129        |
| <b>Annex 3: Note of Informal Meeting: 23 July 2007</b>                     | <b>133</b> |
| Panel 1: Relationships, carers and support                                 | 133        |
| A human rights based approach                                              | 133        |
| Family carers and independent living                                       | 134        |
| Funding, eligibility and access to services                                | 138        |
| Carers                                                                     | 139        |
| Concluding statements                                                      | 139        |
| Panel 2: Access to justice                                                 | 139        |
| Human rights and crimes against people with learning disabilities          | 139        |
| Bullying, Harassment and Hate Crime                                        | 140        |
| Training                                                                   | 141        |
| People with learning disabilities as accused                               | 142        |
| Prisoners with a learning disability                                       | 144        |
| <b>Formal Minutes</b>                                                      | <b>145</b> |
| <b>List of Witnesses</b>                                                   | <b>146</b> |
| <b>List of Written Evidence</b>                                            | <b>147</b> |
| <b>Reports from the Joint Committee on Human Rights in this Parliament</b> | <b>151</b> |



## Summary

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There are growing numbers of adults with learning disabilities in the UK. The extent to which the rights of adults with learning disabilities are being respected raises fundamental issues of humanity, dignity, equality, respect and autonomy: all key human rights principles. The Committee's inquiry was extended and wide-ranging. The Committee wanted to ensure that its inquiry was accessible and relevant for adults with learning disabilities. This Report is accompanied by an Easy Read summary and an audio version of that summary (paragraphs 1-15).

Despite marked improvements in the past thirty years in the lives of adults with learning disabilities, including the closure of long stay hospitals, there have been a number of recent failures in healthcare, including cases of abuse, neglect and ill-treatment of adults with learning disabilities. These, and a number of recent high profile criminal cases, appeared to confirm that adults with learning disabilities are particularly vulnerable to breaches of their human rights (paragraphs 16-29).

The Committee's inquiry received evidence principally from witnesses in England, and so focuses on the policy framework in the 2001 Government White Paper *Valuing People*. This is based on rights, independence, choice, inclusion and a programme of change, but progress has slowed and there is a gap between the Government's policy and the experiences of people in their daily lives. The Committee expects the Government to give the recommendations in this Report serious consideration when it redrafts the current consultation document *Valuing People Now*. It recommends that *Valuing People Now* should promote a "human rights based approach" and provide practical guidance to public authorities on how human rights principles can be used to secure better treatment (paragraphs 30-43).

The evidence seen by the Committee shows it is still necessary to emphasise that adults with learning disabilities have the same human rights as everyone else. It recommends action to promote awareness and a positive approach to the rights of adults with learning disabilities under the Disability Discrimination Act 1995 (as amended) and the Human Rights Act 1998. The Committee recommends that the Equality and Human Rights Commission and the Government should take steps to help adults with learning disabilities understand what these provisions mean for them. The Committee welcomes the decision of the Government to sign the UN Convention on the Rights of Persons with Disabilities, which presents a valuable opportunity to confirm that people with disabilities, and particularly adults with learning disabilities, are entitled to full respect for their human rights. The Committee recommends the Government should ratify this Convention, and its Optional Protocol, without delay (paragraphs 44-77).

Evidence to the Committee suggests that adults with learning difficulties are more liable to social exclusion, poverty and isolation, and that efforts to improve their lives have had little impact on some. The evidence suggests that public authorities, including local authorities and PCTs, are not fully committed to the implementation of the Government's policy in *Valuing People* and that limited resources are undermining attempts to implement the aims of that policy effectively. The Committee recommends the introduction of a positive duty on public authorities to promote respect for human rights. Taking a positive and proactive

approach to the creation of a culture of human rights will encourage a move away from negative attitudes and stereotypes which have “dehumanised” adults with learning disabilities in the past (paragraphs 78-134).

The Committee is concerned that adults with learning disabilities in health and residential settings suffer neglect, abuse, discrimination and indifference. Although the Committee welcomes the announcement by the Department of Health of an independent inquiry into the healthcare of adults with learning disabilities, it considers that the Department of Health could do much more to promote culture change and a human rights-led approach (paragraphs 135-158).

Evidence to the Committee suggests that children of people with learning disabilities are more likely to be removed from the care of their parents. These removals, unless justified and proportionate to a risk to the child, may lead to a serious risk of a breach of the rights of the child and its parents to respect for their private and family lives, as guaranteed by Article 8 ECHR. The Committee recommends proactive and positive action by the Department of Health (paragraphs 159-181).

Witnesses raised significant concerns about the human rights of people with learning difficulties in the criminal justice system. Evidence suggests that people with learning disabilities are very concerned about crime, including hate crimes against people with learning disability. Witnesses told the Committee that people with learning disabilities are not taken seriously and lack confidence in and understanding of the criminal justice system. Witnesses told us that adults with learning disabilities may sometimes serve longer custodial sentences than others convicted of comparable crimes (paragraphs 182-217).

In the Committee’s view, more should be done to reduce barriers to the enjoyment of ordinary life by people with learning difficulties including through the production of more accessible information and independent advocacy, as well as by measures in relation to areas such as voting, communications equipment and support services. It recommends legislation to ensure that all providers of health and social care are considered public authorities for the purpose of the Human Rights Act and are subject to the duty to comply with Convention rights (paragraphs 218-292).

The Committee’s recommendations in this report are based on its view that stronger leadership is urgently needed to create a more positive culture of respect for human rights in the United Kingdom. It calls for practical steps to be taken to promote the rights of adults with learning difficulties in mainstream public services. It considers that the Department of Health and the Office for Disability Issues should work closely together, including to ensure effective cross Government work to place the aims of *Valuing People* in the mainstream and to ensure respect for the human rights of adults with learning disabilities. It encourages the Equality and Human Rights Commission to ensure that the voices and views of adults with learning difficulties play a central role in its work (paragraphs 293-303).

# 1 Introduction

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## Our inquiry

1. The number of adults with learning disabilities in the United Kingdom is growing. People with learning disabilities are generally living longer. More premature babies and children with learning and other disabilities are surviving into adulthood.<sup>1</sup> Recent figures show that spending on social care for adults with learning disabilities doubled during the past decade, yet there has been a growing campaign recently for increased funding as services struggle to cope with demand.<sup>2</sup> The first national survey of people with learning disabilities found that adults with learning disabilities are often socially excluded, have little control over their own lives, and were “more likely than others to have bad things happening in their lives”.<sup>3</sup>

2. Human rights apply to everyone. We have chosen in our recent thematic inquiries to focus on groups which are particularly vulnerable; whose members may have difficulty speaking up for their rights; or who may have difficulty understanding when their rights under equality, human rights and other legislation are being breached. Over the past two years, stark reports on the treatment of adults with learning disabilities in health and social care settings have been published, by the Healthcare Commission and the Commission for Health and Social Care, Mencap and the Disability Rights Commission. Each of these reports raises substantive issues about the compatibility of such treatment with human rights and equality law under the Human Rights Act 1998 (“HRA”) and the Disability Discrimination Act 1995 (as amended), the European Convention on Human Rights (“ECHR”) and other international legal standards. We most recently considered these issues in relation to the treatment of older people in healthcare, in our Report on Older People in Healthcare.<sup>4</sup> In this inquiry, however we have chosen to consider a broader range of issues of relevance to adults with learning disabilities.

3. The extent to which the rights of adults with learning disabilities are currently being respected raises fundamental issues of humanity, dignity, equality, respect and autonomy: all key human rights principles. It also raises other important issues of substantive human rights law such as the right to life (as guaranteed by Article 2 ECHR), the prohibitions on inhuman and degrading treatment (Article 3 ECHR) and unjustified discrimination (Article 14 ECHR), and the right to respect for private and family life (Article 8 ECHR). The treatment of adults with learning disabilities by the criminal justice process may engage the right to a fair hearing (Article 6 ECHR) and due process, and the right to liberty (Article 5 ECHR), rights that are also protected by our common law. A number of inquiries and campaigns about the rights of adults with learning disabilities have recently adopted

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<sup>1</sup> Valuing People: A New Strategy for Learning Disability for the 21<sup>st</sup> Century, Department of Health, Cm 5086 (“*Valuing People*”).

<sup>2</sup> Care Services Improvement Partnership, “Getting to grips with commissioning for people with learning disabilities”, April 2007.

<sup>3</sup> National Statistics and Health and Social Care Information Centre; Adults with Learning Difficulties in England 2003/04, published on 28 September 2005. (“*The National Survey*”).

<sup>4</sup> Eighteenth Report of Session 2006-07, *The Human Rights of Older People in Healthcare*, HL Paper 156-I, HC 378-I.

the title “A life like any other”, or variations on that theme.<sup>5</sup> We have decided to use this inquiry to question whether we are meeting our obligations to respect the human rights of adults with learning disabilities and whether, as a result, adults with learning disabilities in the United Kingdom are likely to be able to lead ordinary lives.

## Learning disabilities or learning difficulties?

4. This inquiry also challenged us as parliamentarians to ensure our inquiry was accessible and relevant for adults with learning disabilities. We made the early decision that we wanted to take evidence directly from a range of people with learning disabilities and to reach as many people as possible during our inquiry. We wanted to work in a way which was accessible and enabled people to tell us their views. A summary of this Report and its conclusions and recommendations is being published in Easy Read, and in an audio format, as part of this process.

5. The first problem we faced was whether to talk about “learning disabilities” or “learning difficulties”. We know that some people prefer the term “learning disabilities” and others prefer the term “learning difficulties”. We have used the term “learning disabilities” in the title of our inquiry to reflect the language used by the Government in its policy papers and used by the Disability Rights Commission in its work. We considered that this term would avoid any confusion with specific learning difficulties associated with education such as problems faced by children and adults with dyslexia. We used the term learning difficulties when working with witnesses who used this term themselves.

6. We are aware that there are a number of debates over the definition of learning disability. We did not adopt a specific definition in our call for evidence, but have been guided in writing this report by the definition set out in *Valuing People*, the English learning disability White Paper, issued by the Department of Health in 2001, namely that learning disability “includes the presence of:

- a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with:
- a reduced ability to cope independently (impaired social functioning);
- which started before adulthood, with a lasting effect on development.”<sup>6</sup>

7. This definition covers people with an autistic spectrum disorder who also have learning disabilities, but excludes those with average or above average intelligence who have an autistic spectrum disorder, like Asperger’s Syndrome.

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<sup>5</sup> See for example, the Community Care Magazine Campaign: Community Care, 17 May 2007 (“A life like any other”), Healthcare Commission, “A Life like no other: A national audit of specialist inpatient healthcare services for people with learning difficulties in England”, 3 December 2007.

<sup>6</sup> *Valuing People*, paras 1.4 – 1.7.

## Terms of reference

8. We called for evidence on how human rights principles were relevant to the treatment of adults with learning disabilities and how they were treated in their daily lives. In particular we sought evidence on the following issues:

- the provision of public services such as healthcare, education, housing and welfare benefits to people with learning disabilities and on the ability of individuals to access such services and the quality of provision;
- the possibility for adults with learning disabilities to form and maintain personal relationships with others (such as partners, parents and children) and the positive obligations of the state which arise in this context;
- the opportunities for people with learning disabilities to participate in the life of their local community and the state's obligation to facilitate participation; and
- the potential of the United Nations Convention on the Rights of Persons with Disabilities (“UN Disability Rights Convention”) to promote the rights of adults with learning disabilities.

9. With the help of Mencap, we issued an Easy Read version of our press notice. In this, we asked people with learning disabilities to tell us about their experiences. After we published this Easy Read version, some people with learning disabilities contacted us to tell us that our three-month deadline to respond was too short. We issued another press notice to extend this deadline by several weeks. We agreed to accept evidence after the deadline and extended the length of our inquiry to allow people with learning disabilities to participate and tell us their views.

## Evidence and visits

10. In the course of this inquiry, we have received almost 200 separate pieces of evidence and correspondence from a wide range of relevant charities, service providers, non-governmental organisations, carers and families, Government departments and, importantly, directly from adults with learning disabilities. We are grateful for all of the evidence we received. Most of this evidence is published in full in a separate volume to this Report. However, a number of the submissions we received contained detailed information about the experiences of people with learning disabilities or their families; some referred to individual cases and challenges in which they had become involved; a significant number of submissions raised recurring themes. Some people wrote to tell us that they wanted to know more about human rights or to tell us about the support they received. A summary of the themes and stories emerging from the correspondence which we have not published is contained in an Annex to this Report.<sup>7</sup>

11. We commenced our inquiry by taking advice from the British Institute for Learning Disabilities on how we might make the oral evidence sessions more accessible for witnesses with learning disabilities. The transcripts of our oral evidence sessions are published, as

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<sup>7</sup> Annex 2. Most of this unpublished material can be consulted in the Parliamentary Archives.

usual, with this Report. In addition, a detailed note of an informal meeting with witnesses is published in an Annex to this Report.<sup>8</sup>

12. In October 2007, we met with adults with learning disabilities, their supporters and families in a number of different settings. We visited Lewisham College, where we spoke with learners and staff in their School of Supported Learning; we met with members of a local KeyRing Housing and Support Network in South East London; and we visited people with more complex and profound learning disabilities at an HFT (Home Farm Trust) resource centre in Bidford-upon-Avon and at home, in supported accommodation, in Evesham. We also met informally with Lambeth People First Self-Advocacy Group and their supporters at the Palace of Westminster. We are very grateful to all those who assisted us in the course of our inquiry.

### **Structure of our report**

13. In Chapter 2, we consider the policy framework within which services for people with learning disabilities should be provided. In Chapter 3, we consider the relevance of human rights principles for people with learning disabilities. Chapter 4 examines the broad scope of the evidence we received during our inquiry and identifies the key concerns raised with us; it explains how each of these concerns has implications for the human rights of adults with learning disabilities; and considers whether in some circumstances a better understanding of human rights standards could lead to a better life experience for adults with learning disabilities. In Chapters 5, 6, 7, and 8, we look at four areas where human rights concerns were particularly acute: the treatment of adults with learning disabilities in health and residential care settings; the treatment of parents with learning disabilities and their children; access to justice for people with learning disabilities; and the barriers to an ordinary life routinely confronted by people with learning disabilities. In Chapter 9, we consider the practical application of human rights principles to the treatment of adults with learning disabilities and the role to be played by central and local Government and the Equality and Human Rights Commission in promoting the creation of a culture of respect for the human rights of adults with learning disabilities. We set out our principal conclusions and recommendations at the end of this Report. An analysis of the relevant human rights standards is contained in an Annex to this Report.<sup>9</sup>

### **Specialist advisers and acknowledgements**

14. We record our particular thanks to Professor Linda Ward and Camilla Parker, our Specialist Advisers for this inquiry.

15. We also wish to thank Mencap for their assistance in the preparation of our first Easy Read Press Notice and the British Institute of Learning Disabilities for their advice on making our inquiry more accessible to people with learning disabilities.

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<sup>8</sup> Annex 3.

<sup>9</sup> Annex 1.

## 2 Adults with learning disabilities: the key issues

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Human rights abuses are going on every day in our communities suffered by people with learning difficulties and it is time something was done about it.

*Andrew Lee, Director, People First (Self-Advocacy)<sup>10</sup>*

16. There have been marked improvements in the lives and circumstances of adults with learning disabilities in the 30 years between the 1971 White Paper, *Better services for the mentally handicapped*,<sup>11</sup> and its successor in England, *Valuing People*.<sup>12</sup> As Ivan Lewis, MP, Minister of State for Care Services, reminded us:

On the whole, the closure of the long-stay mental handicap hospitals was a success and was of great credit to all those involved, and to this country more generally.<sup>13</sup>

17. As a result, many fewer people now live in long stay institutions, segregated away from the rest of society. Many more live in ordinary housing in the community. A minority now have paid jobs, some at a senior level including, for example, the National Co-Director of Learning Disabilities at the Department of Health.<sup>14</sup> Noticeable too is the number of people with learning disabilities who are active in self advocacy groups, speaking their views and getting their voices heard, including at inquiries of this kind, something that was unheard of 30 years ago.

18. But this picture of positive change has been tarnished recently by a string of reports and inquiries which have revealed a darker, and more shocking, side to life for some adults with learning disabilities in the 21st century.

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<sup>10</sup> Speaking at the launch of the Learning Disability Coalition; <http://www.learningdisabilitycoalition.org.uk/aboutus.asp>.

<sup>11</sup> Department of Health and Social Security/Welsh Office, *Better Services for the Mentally Handicapped*, Cmnd 4683, 1971.

<sup>12</sup> Department of Health, *Valuing People: A New Strategy for Learning Disability for the 21<sup>st</sup> Century*, Cm5086, March 2001.

<sup>13</sup> Q 154.

<sup>14</sup> Nicola Smith and Rob Greig are the Co-National Directors for Learning Disabilities. We invited both to give evidence, but Ms Smith was unable to attend. When we refer to the National Co-Director we refer to the evidence of Mr Greig.

## Abuse and neglect

A student with cerebral palsy and learning difficulties at one of Scope's residential schools was recently admitted to hospital for 3 days during the school holidays. The student returned directly to the school from hospital and when staff collected him it was noticeable that he had lost a significant amount of weight. The student stated that he had not been given any food to eat during his 3 day stay. When challenged the hospital responded by stating that they did not know how to feed him.

Scope<sup>15</sup>

19. In July 2006 the Healthcare Commission (HCC) and the Commission for Social Care Inspection (CSCI) published a joint report following their investigation of abuse of people with learning disabilities in the care of Cornwall Partnership NHS Trust.<sup>16</sup> The investigation had been prompted by concerns on the part of East Cornwall Mencap Society. The report described many years of abusive practices at the trust including physical, emotional, environmental and financial abuse and the failure of senior trust executives to tackle it. The investigation team found an over-reliance on medication to control behaviour, as well as illegal and prolonged use of restraint. For example, one person spent 16 hours a day tied to a bed or wheelchair. Institutional abuse was widespread. The report spoke of "whole system failure. The mechanisms that should have protected people living in the trust's services failed."<sup>17</sup>

20. In January 2007 the Healthcare Commission published a report following its investigation of learning disability services provided by Sutton and Merton Primary Care Trust.<sup>18</sup> The investigation was undertaken at the request of the Trust's Chief Executive, following a number of serious incidents including allegations of physical and sexual abuse. The report described outmoded, institutionalised, care which had led to the neglect of people with learning disabilities at the Trust, and generally impoverished and unsatisfactory environments, with lack of space compromising people's privacy and dignity. The inappropriate use of restraint was again identified as a serious matter of concern. Institutional abuse was reported to be prevalent in most parts of the service:

Institutional abuse occurs when the rituals and routines of a service result in the lifestyles and needs of individuals being sacrificed in favour of the needs of the institution.<sup>19</sup>

21. In the wake of the Cornwall report, the Healthcare Commission embarked on the first audit of NHS and independent specialist inpatient healthcare services for people with

<sup>15</sup> Ev 79.

<sup>16</sup> Healthcare Commission and Commission for Social Care Inspection, *Joint Investigation into Cornwall Partnership Trust*, July 2006.

<sup>17</sup> *Ibid*, p 62.

<sup>18</sup> Healthcare Commission, *Investigation into the services for people with learning disabilities provided by Sutton and Mersey Care Trust*, January 2007.

<sup>19</sup> *Ibid*, p6.

learning disabilities in England, in order to identify problems in the sector as a whole, as well as examples of best practice (“the Healthcare Commission Audit”). The report, published in December 2007, found that most services for people with learning disabilities provided poor standards of care, with significant institutional failings depriving people of their human rights and dignity in many instances.<sup>20</sup> Services operated below the radar of the healthcare system, with poor leadership, poor training and no framework to measure the performance of services. People were living in poor physical environments, with few choices in how they lived their lives, and isolated from their communities. While the Commission did not find evidence of physical abuse in any service, it did find that insufficient attention was paid to safeguarding vulnerable people across all aspects of their care.

### Failures in healthcare

Sara’s parents noticed she was showing signs of distress, crying and falling over more frequently. They took her to hospital to investigate what was wrong, but no investigations took place. Sara kept holding her head and was clearly in serious distress, but was only given paracetamol to manage her pain.

Ten days later Sara was screaming in pain and suffered a major seizure. A brain scan revealed an 8cm brain tumour. It was too late to operate, and Sara died. Sara must have been in intense pain, without appropriate treatment or pain relief, for over ten days.

*Mencap*<sup>21</sup>

In general, hospitals’ staff attitudes and awareness of the needs of people with learning difficulties are not good. Some staff are patronising and disrespectful and treat people like children ... Some doctors over simplify things so that people don’t get the right information. Generally doctors talk too fast, use jargon and don’t give people enough time.

*Monica Hunter, Chairperson, People First (Scotland)*<sup>22</sup>

22. In 2006 the Disability Rights Commission (DRC) published the report of its formal investigation into the inequalities in physical health experienced by people with mental health problems and those with learning disabilities, *Equal Treatment: Closing the Gap*.<sup>23</sup> It showed that people with learning disabilities “die younger than other citizens”, and had

<sup>20</sup> Healthcare Commission, *A life like no other: a national audit of specialist inpatient healthcare services for people with learning difficulties in England*, December 2007.

<sup>21</sup> Ev 140.

<sup>22</sup> Ev 321.

<sup>23</sup> Disability Rights Commission, *Equal treatment: Closing the Gap*, 2006.

high rates of unmet health needs, “which may contribute to early death.” The report highlighted a “fatal complacency” in the NHS which had contributed to this situation.<sup>24</sup>

23. In 2007 a report by Mencap, *Death by Indifference*, described the cases of six people with a learning disability who had died, following unsatisfactory treatment while in the care of the NHS.<sup>25</sup> The report argued that “their deaths were avoidable...and occurred because of discrimination, indifference, lack of training and a very poor understanding of the needs of people with a learning disability”.<sup>26</sup> It prompted the Minister for Care Services to comment that there appeared to be “systemic indifference” in the NHS towards people with learning disabilities.<sup>27</sup>

24. Following these two reports, the Secretary of State for Health ordered an independent inquiry into access to healthcare for people with learning disabilities to identify the action needed to ensure adults and children with learning disabilities receive appropriate treatment in acute medical (hospital) care and general primary care. The inquiry was established on 31 May 2007 and is due to report in June 2008.<sup>28</sup> The Health Service Ombudsman for England is also conducting an independent inquiry into each of the six cases highlighted in the Mencap report.

## Victims of crime

In a particularly disturbing murder case involving a man with profound learning difficulties, a teenage girl and two men tortured 38-year-old Steven Hoskin before forcing him to his death from a 100ft viaduct in St Austell, Cornwall ... Yesterday, they were jailed for murder and manslaughter. As well as drugging him with 70 paracetamol tablets, burning him with cigarettes and forcing him to walk around on a dog lead, the offenders made Mr Hoskin confess to being a paedophile before killing him.

*Guardian, Society, 31 July 2007*

25. In the last year there has also been widespread media coverage of the deaths of a number of people with learning disabilities, following serious assaults and abuse. They include Steven Hoskin (see above); Kevin Davies, who was locked in a garden shed in Gloucestershire, where he was beaten, burned and humiliated before he died; Raymond Atherton, who was subjected to a long campaign of physical abuse at the hands of local teenagers before being beaten and thrown into the River Mersey in Cheshire, where he died; and Brent Martin, who was beaten up and left to die on the street in Sunderland. These cases gained public attention.<sup>29</sup> They prompted increased concern on the part of

<sup>24</sup> Ibid, p29.

<sup>25</sup> Mencap, *Death by Indifference*, 2007.

<sup>26</sup> Ibid, p.4.

<sup>27</sup> Community Care Magazine “Government launches inquiry after Lewis speaker of NHS ‘indifference’” 15 March 2007.

<sup>28</sup> *Independent Inquiry into Access to Healthcare for People with Learning Disabilities*, chaired by Sir Jonathan Michael.

<sup>29</sup> See for example; BBC News: ‘Feral boy, jailed for killing’, 3 April 2007 (Raymond Atherton) and BBC News: ‘Boy convicted of £5 bet murder’, 22 January 2008 (Brent Martin).

people with learning disabilities and their organisations about whether the victims had been subjected to crime because they had learning disabilities. The Crown Prosecution Service launched a policy for prosecuting such crimes in February 2007.<sup>30</sup> In December 2007, it was announced that the Home Office planned to produce good practice guidance for the criminal justice system and local authorities to address issues of hate crime against people with learning disabilities.<sup>31</sup>

## Are people with learning disabilities especially vulnerable to infringements of their human rights?

It is hard to make decisions. Sometimes help is needed. Nobody listens. People in the street do not understand. We should be treated as individuals, this would help us take control.

*Speakeasy N.O.W. Self-Advocacy Organisation*<sup>32</sup>

26. In the light of each of these high-profile instances and reports of abuse, ill-treatment and discrimination against people with learning disabilities, we consider that it is timely for Parliament to consider the extent to which the United Kingdom is meeting its domestic and international obligations to respect and protect the human rights of adults with learning disabilities.

27. The evidence we have received confirms that adults with learning disabilities are particularly vulnerable to a lack of respect for their human rights.

- People with learning disabilities may not be aware of their human rights because information about their rights is not easily available in simple, easy to understand formats.<sup>33</sup>
- Expectations have traditionally been low for people with learning disabilities, so that the lack of a job, an impoverished home environment, the absence of social relationships, and a lack of privacy and dignity, are often accepted without comment. As Rob Greig, National Co-Director for Learning Disabilities, told us:

we need to remember that we are talking about people who on the whole have not only had their rights denied for centuries, but have actually lived in an environment where they have been ... taught not to have great expectations in life.<sup>34</sup>

- The existence of negative attitudes and prejudice may mean that breaches of their human rights are not treated seriously. For example, Respond, the Ann Craft Trust and Voice UK told us:

<sup>30</sup> Policy for Prosecuting Cases of Disability Hate Crime, Crown Prosecution Service, February 2007.

<sup>31</sup> Department of Health, *Valuing People Now: From Progress to Transformation*, December 2007.

<sup>32</sup> Ev 67.

<sup>33</sup> Ev 232.

<sup>34</sup> Q 120.

an intrinsic part of this prejudice is a feeling that people with learning disabilities are worth less than those without learning disabilities and so are deserving of less respect for their rights.<sup>35</sup>

- People with learning disabilities are often socially marginalised and isolated. They may live in segregated settings with few, if any, social relationships with people living in the wider community. Infringements of their human rights are thus less likely to be observed or addressed.<sup>36</sup>
- People with learning disabilities tend to be dependent on paid or unpaid carers.<sup>37</sup> This makes it hard for them to challenge the care they receive, even if they feel something is not right.
- Difficulties in understanding and communication may mean that people with learning disabilities may be more susceptible to manipulation and exploitation and so vulnerable to certain kinds of crime and abuse.<sup>38</sup>
- People with learning disabilities are less likely than other people to be aware of whether an action against them abuses their human rights,<sup>39</sup> to make a complaint about any such infringements, or to report a crime against themselves.<sup>40</sup> They consider that they are also less likely to be believed, even if they do so.<sup>41</sup> In the words of one witness:

For many adults with learning disabilities, the violation of their human rights is seen as a normal part of their everyday lives.<sup>42</sup>

28. Witnesses told us that the human rights of some groups of people with learning disabilities are likely to be particularly at risk. These include people with profound and multiple disabilities, who may not be able to communicate through speech;<sup>43</sup> people whose behaviour poses a challenge to the staff and services that work with them;<sup>44</sup> people from black and minority ethnic communities, who may not find accessible information or appropriate and culturally sympathetic support readily available;<sup>45</sup> and people who have been placed in service settings many miles away from their families and communities of origin.<sup>46</sup> Our evidence suggests that such people face additional hurdles in securing support for their human rights or in disclosing infringements of them.

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<sup>35</sup> Ev 279, para 1.3.2.

<sup>36</sup> Ev 247. See also the *National Survey*, Executive Summary, Pages 4 – 11.

<sup>37</sup> Ev 233.

<sup>38</sup> Ev 99; Ev 205, page 6.

<sup>39</sup> Q 2.

<sup>40</sup> Ev 247, Ev 411.

<sup>41</sup> Ev 247.

<sup>42</sup> Ev 247, para 1.1.

<sup>43</sup> Ev 203.

<sup>44</sup> Ev 79.

<sup>45</sup> Ev 216; Ev 222.

<sup>46</sup> Ev 245.

29. In this report we include short examples, or stories, from the evidence we received to illustrate the wide range of ways in which the human rights of people with learning disabilities are not being respected, despite the positive developments in policies affecting people with learning disabilities in the last few years.

## The policy context

30. The overall direction of policy guiding services for people with learning disabilities is similar in all four nations of the UK – a commitment to enabling people with learning disabilities to live as equal citizens in the community alongside their non-disabled peers, with choice and control over their lives, and the support they need to enable this. This policy is set out in England in *Valuing People*,<sup>47</sup> in Scotland in *The Same as You?*<sup>48</sup> and in Wales in the recent *Statement on Policy and Practice for Adults with a Learning Disability*.<sup>49</sup> In Northern Ireland, The Bamford Review of Mental Health and Learning Disability published its final report on legislative reform (including proposals on mental capacity legislation) in August 2007.<sup>50</sup> This was the last of a series of 11 reports produced over a period of five years, including *Equal Lives: Review of Policy and Services for People with a Learning Disability in Northern Ireland* in September 2005, *Human Rights and Equality of Opportunity* in October 2006, and *Promoting the Social Inclusion of People with a Mental Health Problem or a Learning Disability* in August 2007. The values base and overall policy goals in the four countries are similar, though only the Northern Ireland reports refer explicitly to human rights to any degree. The service frameworks for implementing policy on the ground differ from country to country.

**31. We received evidence from across the UK, but most was from organisations and individuals in England. Consequently, this Report will focus largely on the policy framework in *Valuing People*. However, the human rights standards discussed in this Report are universal. We consider that most of the conclusions that can be drawn from the evidence are equally relevant to all four countries of the UK. Equally, we hope that our recommendations and conclusions will inform the development of policy and practice by each of the devolved administrations, as well as central Government.**

32. Our concern, is that the provisions of the Human Rights Act have not been implemented effectively, or with adequate guidance from Government. As a result, the Act has been insufficiently understood and applied.<sup>51</sup> By taking a positive approach to their human rights obligations under the Human Rights Act, the Disability Discrimination Act (as amended) and the common law, public authorities could improve the delivery of public services for all, particularly for vulnerable groups for whom they should offer protection, like adults with learning disabilities. We consider that the creation of a culture of respect

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<sup>47</sup> Department of Health, *Valuing People: A New Strategy for Learning Disability for the 21<sup>st</sup> Century*, Cm 5086, March 2001.

<sup>48</sup> Scottish Executive, *The same as you? A review of services for people with learning disabilities*, 2000.

<sup>49</sup> Welsh Assembly Government, *Statement on Policy and Practice for Adults with a Learning Disability*, 2007.

<sup>50</sup> The Bamford Review of Mental Health and Learning Disability (Northern Ireland), *A Comprehensive Legislative Framework*, August 2007.

<sup>51</sup> Eighteenth Report of Session 2006-07, *The Human Rights of Older People in Healthcare*, HL Paper 156-I, HC 378-I, para 67.

for human rights will help lead towards a society where everyone, including adults with learning disabilities, is treated fairly, with equality and with dignity.

### Where we are now: Are we valuing people?

33. Since 2001, the delivery of services and support for adults with learning disabilities in England has been framed by the cross government *Valuing People* White Paper.<sup>52</sup> Its key message was that people with learning disabilities are, above all else, people and citizens. The role of public services was to help them live full and equal lives in the community. The White Paper had at its heart four underlying principles – rights, independence, choice and inclusion – and an ambitious programme of work to deliver change in these areas. This included commitments to reducing health inequalities, increasing the range and choice of housing available, modernising day services and increasing access to employment. New mechanisms for delivery were also introduced, such as person centred planning, health action planning for individuals, and the establishment of multi-agency Learning Disability Partnership Boards in local areas. All these provisions should have improved the chances of people with learning disabilities becoming enabled to enjoy their human rights. The lack of explicit reference to human rights in the White Paper (apart from a passing reference to the Human Rights Act 1998, along with other relevant legislation, in the section entitled “Our Values”) is noticeable and unfortunate, given the White Paper’s vision that:

All public services will treat people with learning disabilities as individuals with respect for their dignity, and challenge discrimination on all grounds including disability. People with learning disabilities will also receive the full protection of the law when necessary.<sup>53</sup>

34. Despite the good intentions of *Valuing People*, and the positive reception to it in the field, a review of progress on its implementation four years later, entitled *The Story So Far*, revealed that not much had changed for many people.<sup>54</sup> Many mainstream public services had not taken its messages on board. Some groups (like those with complex support needs) had missed out on progress. Perhaps, most significantly, the review pointed out that:

Most people’s lives are still not what a non-disabled person would say was OK for themselves. Society is beginning to understand that people are equal citizens – but making this real is quite a long way off.<sup>55</sup>

35. *The Story So Far* revealed progress in some areas. People were being listened to more both about their individual lives and in service planning. Person centred planning, done properly, was making a difference to people’s lives. The Supporting People programme (designed to help vulnerable people retain their housing tenancies) had helped many to live more independently.<sup>56</sup> Direct payments (through which people were given the cash

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<sup>52</sup> Department of Health, *Valuing People: A New Strategy for Learning Disability for the 21<sup>st</sup> Century*, Cm 5086, March 2001.

<sup>53</sup> *Ibid*, para.2.2.

<sup>54</sup> Valuing People Support Team, *The Story So Far*.,2005.

<sup>55</sup> *Ibid*, para 1.4.

<sup>56</sup> Department of Health, *Valuing People Now*, para 1.6.

equivalent of the cost of the services they were assessed as needing, so they could purchase their own choice of support) had helped to change some people's lives.<sup>57</sup> But in other areas (eg access to paid work and to good quality healthcare) progress had been disappointing.<sup>58</sup>

36. In May 2007, the Government announced its decision to “refresh” its policy with the publication of *Valuing People Now* – a consultative draft of the Government's intentions for improving services for people with learning disabilities between 2008 – 2011.

37. *Valuing People Now* was published after our inquiry concluded and we have not taken evidence on the substance of the consultation document. The Government's consultation process will finish at the end of March 2008.<sup>59</sup>

38. *Valuing People Now* identifies five priorities for action: “... personalisation, what people do during the day, better health, access to housing and making sure that change happens”.<sup>60</sup> A table at the end of each section summarises the different goals, and how progress on each will be measured. **In the light of the evidence which we received on the gap between the aims of *Valuing People* and the experience of adults with learning disabilities, which we consider below in Chapter 4, we are concerned that in *Valuing People Now* there appear to be few measurable targets for action nor precise proposals for monitoring progress on their achievement.**

39. The Minister for Care Services reassured us that this document would focus on human rights.<sup>61</sup> We were disappointed that references to human rights are noticeably absent from the main body of the document, although their salience to what is proposed is recognised in the Secretary of State for Health's “Foreword”:

There is no question that it is a human rights issue that all people with learning disabilities [should] have the choices and control over their lives that so many of us take for granted – a life like any other.<sup>62</sup>

40. **We are pleased to note that the Government is committed to “fully consider and respond to the conclusions” of our Report in the course of formulating their priorities for 2008 - 2011. We expect the Government to give the recommendations and conclusions of our Report serious consideration during preparation of the final version of *Valuing People Now* and in setting its priorities for action for the next three years. We consider that *Valuing People Now* presents a valuable opportunity for the Department of Health to take a positive approach towards the promotion of the understanding and protection of the human rights of adults with learning disabilities. We recommend that, when redrafted after consultation, *Valuing People Now* should explicitly promote a “human rights based approach” to public authorities' duties under**

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<sup>57</sup> Ibid, para 1.7

<sup>58</sup> Ibid, para 9.2.9.

<sup>59</sup> Ibid, para 9.2.9.

<sup>60</sup> Ibid, 2007, Foreword.

<sup>61</sup> Q 187.

<sup>62</sup> Department of Health, *Valuing People Now*, Foreword.

**the Human Rights Act; and should provide practical guidance for public authorities on the effective implementation of those duties.**

41. A number of other Government policy proposals have been relevant to our work on this inquiry. The core issue of increasing people's choice and control is central to the government's strategy on *Improving the Life Chances of Disabled People*, both generally and in its wider plans for health and social care reform, contained in *Our Health, Our Care, Our Say*. The former report established the cross government Office for Disability Issues ("ODI") which will publish its five year Independent Living Strategy in 2008. Both reports made commitments to modernising social care and developing independent budgets to give people more choice and control over the supports they need to live independently. "Independent living" was defined as:

all disabled people having the same choice, control and freedom as any other citizen – at home, at work, and as members of the community. This does not necessarily mean disabled people 'doing everything for themselves', but it does mean that any practical assistance people need should be based on their own choices and aspirations.<sup>63</sup>

42. We note that a number of new Government proposals have been announced during the progress of this inquiry. For example, in December 2007, after the conclusion of our evidence taking, the Secretary of State for Health announced the government's vision and commitment for the transformation of Adult Social Care. This was to "set out and support the Government's commitment to independent living for all adults" so that:

Over time, people who use social care services and their families will increasingly shape and commission their own services. Personal budgets will ensure people receiving public funding use available resources to choose their own support services.<sup>64</sup>

43. Against the backdrop of this and other policy developments, designed both to improve the choice and control exercised by people with learning disabilities over their support, and to safeguard them where they are vulnerable, there has nonetheless been substantial evidence of strain on local services and carers. Increasing numbers of local authorities have tightened their eligibility criteria as a result of resource constraints and an increase in the numbers of people with learning disabilities needing support. *Valuing People Now* includes a commitment to "work to fully assess the impact of the increasing numbers of people with learning disabilities on demand for, and therefore the cost of, services" but makes no reference to the issue of tightening eligibility criteria. We return to this issue in Chapter 4.

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<sup>63</sup> See Prime Minister's Strategy Unit, *Improving the Life Chances of Disabled People*, January 2005, p 17. This is based directly on definition adopted by the Disability Rights Commission.

<sup>64</sup> Department of Health, *Putting People First: a shared vision and commitment to the transformation of adult social care*, December 2007, Press Notice, 10 December 2007.

### 3 Why do human rights matter?

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Training around rights will help people with learning disabilities to get their human rights.

*Cornwall People First*<sup>65</sup>

The extent to which society looks down on us contributes to the fact that throughout our lives people with learning difficulties do not get their human rights, and yet there is no public outcry, no-one up in arms about how little choice we have over our everyday lives.

*Andrew Lee, Director, People First (Self-Advocacy)*<sup>66</sup>

44. In the rest of this Report, we consider the treatment of adults with learning disabilities, and the evidence we have received. **We are disappointed that, at the start of the 21st century, almost ten years after the introduction of the Human Rights Act, and over a year since the introduction of the Disability Equality Duty, this evidence convinces us that we need to emphasise that adults with learning disabilities have the same human rights as everyone else; and that they are entitled to freedom, respect, equality, dignity and autonomy in their everyday lives.** In an Annex to this Report, we outline the various human rights laws and standards which are relevant to our inquiry. In that Annex, we refer not only to the provisions of the Human Rights Act and to the common law, but also to the provisions of the Disability Discrimination Act (as amended), including the positive Disability Equality Duty and the UN Disability Rights Convention.

#### What does the Human Rights Act add?

45. We have consistently expressed our view that the Human Rights Act is important in the development of institutional and Government policies and practices, and in the improvement of public services.<sup>67</sup> For example, in our Report on the *Human Rights of Older People in Healthcare*, we said:

We see the purpose of the Human Rights Act, not as an end in itself, but as a tool that can and should be used in law, policy and practice to enable [...] social justice goals to be achieved.<sup>68</sup>

46. We consider that the Human Rights Act provides ‘a legal framework for service providers to abide by and empower service users to demand that they are treated with

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<sup>65</sup> Annex 2, para 10.

<sup>66</sup> Q 1.

<sup>67</sup> See for example, Sixth Report of Session 2002-03, *The Case for a Human Rights Commission*, HL 67-1, HC 489-I, para 9.

<sup>68</sup> Eighteenth Report of Session 2006-07, *The Human Rights of Older People in Healthcare*, HL Paper 156-I, HC 378-I, para 69.

respect for their dignity'.<sup>69</sup> The Human Rights Act empowers users of public services who may be placed in situations where they are vulnerable to abuse. We consider that these conclusions apply with equal force to people with learning disabilities.

47. Joanna Perry, from Values into Action, put it well when she told us:

Sometimes for staff, in particular staff working with people with learning difficulties in institutional settings, especially in long-stay hospitals, sometimes in the institutional world common sense is not the law of the land, it is not what rules how people are treated. Sometimes staff need help to see how human rights obligations can help them problem-solve.<sup>70</sup>

48. She gave us the example of a man who liked to go out in his garden, but who also liked to make a lot of noise. The neighbours complained and the response of his care home staff was to keep him indoors:

We helped the staff use the framework of human rights, which puts everyone's rights on the same footing, to see how his rights were equal to the neighbour's rights ... and to come to a compromise. The staff [went from] thinking "Oh, human rights. That's just another thing we are going to have to deal with", to seeing how it could be used to problem-solve some very difficult situations, and it can be used from day-to-day stuff like that to life and death decisions.

49. The National Co-Director for Learning Disabilities told us that adopting a rights based approach to *Valuing People* was right. He explained:

I think it is the right approach, because getting people to understand that this is not something you do because you want to be nice to disabled people, but is actually their rights as equal citizens, and building that into working patterns, is the way forward.<sup>71</sup>

50. Witnesses told us human rights had a role to play, but that there were a number of barriers to a better deal for adults with learning disabilities.<sup>72</sup> These included failure by Government to secure the effective implementation of *Valuing People*, lack of funding, and negative attitudes (which we consider in Chapter 4, below).

51. We recognise that it may be particularly difficult to empower people with learning disabilities to speak up for their rights under the Human Rights Act. As Andrew Lee, Director, People First (Self-Advocacy) told us:

A lot of people do not know what their human rights are and, for example, asking about human rights and public services such as housing will not mean much.<sup>73</sup>

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<sup>69</sup> Ibid, para 93.

<sup>70</sup> Q 69.

<sup>71</sup> Q 119.

<sup>72</sup> Qs 8-9.

<sup>73</sup> Q 2. See also Ev 233.

52. We consider that it is part of the role of Government to ensure that human rights principles and standards are accessible. Particular steps may need to be taken to ensure that adults with learning disabilities are assisted to understand human rights, including through the provision of accessible information and advocacy (which we consider below in Chapter 8). Values into Action told us that their “Rights into Action” project had worked with adults with learning disabilities and had:

helped them get the language together to talk to people who had control over their lives and to challenge these quite pervasive daily ways that people’s rights were being interfered with. There are many examples of this. There should be a lot more and it is absolutely possible for people to understand the concepts and make them real.<sup>74</sup>

53. **We recently made a number of recommendations to Government on “the transformative power of the Human Rights Act”. In plain English, we told the Government and others what we thought they needed to do to make the Human Rights Act work for everyone. We have called upon the Government, the Equality and Human Rights Commission, other public bodies and voluntary organisations to champion publicly how a better understanding of human rights principles could improve health and social care services.** Specifically, we recommended that the Equality and Human Rights Commission as part of their duty to “promote understanding of human rights” should ensure that this understanding is widely disseminated.<sup>75</sup> **We consider that when fulfilling this duty, the Equality and Human Rights Commission has a responsibility to engage proactively with those who are most vulnerable to breaches of their human rights and those who are less likely to be able to understand what human rights mean for them, including adults with learning disabilities. We recommend that the Commission take steps to ensure that adults with learning disabilities are aware of their rights under the Human Rights Act and the Disability Discrimination Act (as amended).**

54. However, despite the welcome establishment of the Equality and Human Rights Commission, we consider that Government retains a primary responsibility to ensure that we all understand the human rights framework within which they, and service providers, operate. **We recommend that the Minister for Care Services, the Office for Disability Issues and the Ministry of Justice together develop a strategy on how to help vulnerable people, including adults with learning disabilities, understand what the statutory duties in the Human Rights Act and the Disability Equality Duty mean for them.**

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<sup>74</sup> Q 49.

<sup>75</sup> Eighteenth Report of Session 2006-07, *The Human Rights of Older People in Healthcare*, HL Paper 156-I, HC 378-I

## Disability, equality and human rights

The Disability Equality Duty is, in my opinion, possibly the single most important piece of policy or legislation that could impact upon the lives of people with learning disabilities, more so than the *Valuing People* policy itself ... The difficulty I see at the moment is there is a low level of awareness of the Disability Equality Duty across the country.

*The National Co-Director for Learning Disabilities*<sup>76</sup>

55. The important connection between human rights and equality was emphasised by the Minister for Disabled People in her evidence to this inquiry:

The Government's aim of achieving disability equality and full participation in society for disabled people within a generation (by 2025) as described in the Life Chances report ... is fully consistent with the [UN Disability Rights Convention] aim of protecting disabled people's human rights.<sup>77</sup>

**56. We consider that the statutory duties under the Disability Discrimination Act (as amended), and specifically, the Disability Equality Duty, complement the HRA. Together they form a powerful means of effecting positive change. If both are understood and implemented properly they can underpin and promote the agenda set by the Government for improving the life chances of people with learning disabilities.**

57. Unfortunately, a number of our witnesses confirmed that there is a low level of awareness of the implications of the Disability Equality Duty among people with learning disabilities, their carers and supporters and, more worryingly, on the part of service providers and public authorities. Ms Eve Rank, Disability Rights Commissioner, gave a helpful illustration:

Some local authorities do not know about the Disability Equality Duty. For example, last week I had alterations done to my bathroom, because my husband is disabled, and I am disabled a little bit for the next six weeks. I asked about the equality duty and asked if he was involved with people with learning disabilities and he did not know what it was. That is the Adaptations Manager. I also asked somebody from Bedfordshire social services this morning and they did not know.<sup>78</sup>

58. She added:

However, it has only just recently come into force, since December, so it is early days to tell whether it is working or not but it is great fun asking the people who I know if they know about it. I think it is really important that they do involve people with learning difficulties in their equality schemes. The one problem they might have is that they do not know how to do it, because it is the first time they have got to

<sup>76</sup> Q 135.

<sup>77</sup> Ev 388, para 11.

<sup>78</sup> Q 27.

involve people, so they need training, and the only people to give this training to get people involved are the people with learning difficulties themselves, because they are the experts.<sup>79</sup>

59. We asked the Minister for Disabled People to explain why, given that the Disability Equality Duty is so important for adults with learning disabilities, there was so little awareness of the requirements of the duty among public authorities. She told us that there was a distinction between awareness and compliance with the duty at a “high level within public authorities”, and formal compliance by, for example, “the publication of a disability equality scheme, etc”, and “a bigger issue” of cultural change. She explained that although the purpose of the Disability Equality Duty was cultural change, radical change could not happen overnight.<sup>80</sup>

**60. We are concerned that, one year after the introduction of the Disability Equality Duty, the evidence we have received suggests a clear distinction between formal compliance by public authorities and a failure to take a positive approach to the duty on the ground.** Despite the Minister’s reassurance that the Government did not consider compliance with the Disability Equality Duty should be a “tick-box” exercise, we are concerned that without proactive work on the part of the Office for Disability Issues and the Equality and Human Rights Commission, this is precisely what will happen. We welcome the commitment of the Minister for Disabled People to work together with the Equality and Human Rights Commission to ensure that the Disability Equality Duty “is not left on a pile somewhere”.<sup>81</sup> However, when we asked for the Government’s plans to improve awareness and ensure positive compliance, we were disappointed to see that the plan includes Ministerial speeches and a “new wave” of other unspecified “activities”. **We recommend that the Office for Disability Issues work closely with the Equality and Human Rights Commission to champion publicly a broad, positive approach to the Disability Equality Duty. This should involve a strategy to ensure that other public bodies, and their staff, understand how the proactive implementation of the duty can improve service provision for adults with learning disabilities and others.**

61. Throughout this inquiry witnesses have highlighted the importance of the Disability Equality Duty and its huge potential to bring about positive change to the lives of people with learning disabilities. Witnesses expressed their concerns that the proposals in the Government’s Single Equality Bill consultation document concerning the public sector equality duties may weaken the existing disability equality duty.<sup>82</sup> **We urge the Government to ensure that any amendment to existing positive equality duties should strengthen rather than undermine their effectiveness.**

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<sup>79</sup> Ibid.

<sup>80</sup> Q 188.

<sup>81</sup> Ibid.

<sup>82</sup> Department for Communities and Local Government, *Discrimination Law Review A Framework for Fairness: Proposals for a Single Equality Bill for Great Britain*, June 2007. See Annex 3, para 2; Ev 333.

## UN Convention on the Rights of Persons with Disabilities

I don't know much about the Convention on the human rights of people with disabilities but I do feel strongly that everyone with a disability should have equal rights to those who don't have disabilities.

*A person with learning disabilities*<sup>83</sup>

62. The new UN Convention on the Rights of Persons with Disabilities highlights the strong links between human rights and equality. For example Article 4 (General obligations) provides that States are required to take steps in order to:

Ensure and promote the full realization of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability.

63. The Minister for Disabled People succinctly summed up the importance of this new international human rights treaty:

The Convention is a powerful statement that disabled people are fully entitled to the same human rights and fundamental freedoms as others.<sup>84</sup>

64. Sonia Sceats from British Institute of Human Rights ("BIHR") told us that ratification of the UN Disability Rights Convention:

Will send an incredibly strong signal not only to people with learning disabilities but disabled people more generally and to our community about the importance we set on the rights that belong to disabled people. Many people have traditionally seen disabled people through the lens of charity and so forth and this Convention is sending a very strong signal that disabled people are rights holders. This is very important.<sup>85</sup>

65. Inclusion International, an international organisation which represents the interests of people with learning disabilities, told us:

For people with [learning disabilities] and their families, the challenge of this Convention will be to have State parties and other groups recognise that the Convention includes and must protect the rights of people who cannot speak for themselves....For people with [learning disabilities] and their families the Convention provides an opportunity to develop an aspirational instrument with a vision for the future and can transform the way in which our societies are structures and organised in order to be inclusive.<sup>86</sup>

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<sup>83</sup> Annex 2, para 11.

<sup>84</sup> Q 155.

<sup>85</sup> Q 73.

<sup>86</sup> Ev 190-191. The quote refers to "intellectual disabilities", a term used by some international organisations to refer to learning disabilities.

**66. We agree that the UN Disability Rights Convention presents a valuable opportunity to confirm that disabled people, including adults with learning disabilities, are entitled to full respect for their human rights.**

67. The United Kingdom has signed the Convention, but has not ratified it. Having stressed the importance of the UN Disability Rights Convention to us, Anne McGuire MP, Minister for Disabled People commented:

I am under no illusion that making a reality of the new Convention in this way represents an enormous challenge but it is a challenge that we are committed to meeting. We need to build services around disabled people which support them in a way that they want to be supported and not expect them to live in a box that other people have created for them.<sup>87</sup>

68. In her evidence, the Minister told us that it was the Government's intention to ratify the Convention by the end of 2008.<sup>88</sup>

**69. We welcome the Government's commitment to ratify the UN Disability Rights Convention. However, we are mystified by the reason given for the Government's delay in ratifying this treaty.** We wrote to the Minister earlier this year calling on the Government to ratify the Convention and asking for a timetable for ratification.<sup>89</sup> The Minister told us that this was the first human rights treaty that the Government had considered under "which organisations like the European Community share competence with Member States". She explained that "there is a need to coordinate action with the Community...and with other member states ... So the timetable is not within our control".<sup>90</sup> When we asked the Minister to explain whether there were barriers to ratification, such as to cause delay till the end of 2008, she told us: "we also have to ensure that we are in fact compliant and can meet our responsibilities". She said told us that she couldn't tell us about any specific barriers to ratification, but that she was working on plans for ratification with other departments.<sup>91</sup>

**70. We recommend that either the Government ratifies the UN Disability Rights Convention and its Optional Protocol without further delay, or provides clear and unambiguous details of any specific impediments to immediate ratification. We will continue to monitor progress towards ratification. We will be deeply concerned if the Government does not meet the goal that the Minister for Disabled People has set, namely, ratification before the end of 2008.**

## Independent living and human rights

71. Earlier in this chapter we referred to 'independent living', adopting the Disability Rights Commission's definition. Many of our witnesses told us that a right to "independent

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<sup>87</sup> Q 155.

<sup>88</sup> Ibid.

<sup>89</sup> Ev 385.

<sup>90</sup> Ev 386.

<sup>91</sup> Q 190.

living” was important for people with learning disabilities. Some expressed their support for a Private Member’s Bill, the Independent Living Bill, introduced by Lord Ashley of Stoke.<sup>92</sup> For example, both the Disability Rights Commission and Andrew Lee, Director, People First (Self-Advocacy), told us how important they thought this Bill was, as it secured the right of people with learning disabilities to support for independent living.<sup>93</sup>

72. One of our witnesses, Rescare, expressed some concern about the term, ‘independent living’, emphasising that not everyone can live independently. Rescare told us that the extent of the dependency of some people with learning disabilities is often overlooked in considering supported or independent living.<sup>94</sup> When we refer to independent living, we refer to the Disability Rights Commission interpretation, which promotes choice and autonomy for people with disabilities in their daily lives. This may mean different things for different people. It should not be confused with situations where people with learning disabilities have been moved to supported living in the community without adequate support. One of the first things that we learned in this inquiry was that a “one size fits all approach” was not appropriate.

73. We consider that the principles of independent living and promoting the participation of disabled people in community life are core themes of the UN Disability Rights Convention. It has a clear basis in other human rights standards and principles, such as freedom, equality and autonomy. Article 19 (Living independently and being included in the community) of the UN Disability Rights Convention provides that States:

[...] recognize the equal right of all persons with disabilities to live in the community, with choices equal to others and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community.

74. Sonya Sceats, Policy Officer at BIHR put it well when she said that the concept of independent living ‘is something that you can find resonating in the text of the UN Convention’.<sup>95</sup>

75. The Minister for Disabled People told us:

“All of our policies at the moment are driving towards independent living.”

76. The Minister for Care Services added:

“We want the same missionary zeal amongst as many people as possible in terms of the right to independent living, and that in a sense is our next challenge.”<sup>96</sup>

**77. We welcome the commitment expressed by the Minister for Care Services and the Minister for Disabled People, to the principle of independent living. We await the**

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<sup>92</sup> See for example Ev 85, Ev 289.

<sup>93</sup> Q 1 (Andrew Lee), Q 11 (Andrew Lee), Q42 (Mr Shrimpton)

<sup>94</sup> Annex 3, para 17-18 (Richard Jackson, Rescare); Ev 55.

<sup>95</sup> Q 74.

<sup>96</sup> Q 177.

**results of the Government's Independent Living Review, with interest. We recommend that the Government consider the outcomes of that review, and the need for any further policy or legislative change, as part of their commitment to review the UK's domestic compliance with the UN Disability Rights Convention.**

## 4 Living with a learning disability

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I think of life as a person with learning difficulties as being taken to watch a football match, where life is that football match, and never being allowed to join in. People with learning difficulties have the same dreams, inspirations and aspirations as everyone else but we are held back from engaging in life. If you think of your most cherished moments in life, of the things that you still look back on and smile, I expect it is something that people with learning difficulties would get held back from doing.

*Andrew Lee, Director, People First (Self-Advocacy)*<sup>97</sup>

I moved to [a new home]... where people were bad the staff said they could not stay up. I was there 8 years. I used to run away – it was hell there it was like a prison.

*A person with learning disabilities*<sup>98</sup>

78. We heard examples of both good and bad experiences and received evidence on most aspects of life with a learning disability, including:

- access to public and other services (e.g. access to healthcare, education, transport, benefits, social care and support);<sup>99</sup>
- access to housing and choosing where to live;<sup>100</sup>
- access to paid employment;<sup>101</sup>
- relationships with friends and family and sexual or other personal relationships;<sup>102</sup>
- participation in decision-making, speaking up and making complaints;<sup>103</sup>
- playing a part in the local community.<sup>104</sup>

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<sup>97</sup> Q 1.

<sup>98</sup> Annex 2, para 5.

<sup>99</sup> Ev 48, 50, 52, 66, 68, 82, 408.

<sup>100</sup> Ev 55, 84, 92, 110, 116.

<sup>101</sup> Ev 326, 379, 391, 410.

<sup>102</sup> Ev 50, 56, 242, 256.

<sup>103</sup> Ev 116, 219, 238-239, 241, 411.

<sup>104</sup> We have summarised some of the evidence we received from people with learning disabilities, their families and supporters in Annex 2; See also Ev 56.

## Access to public and other services

When group members can't do something they want to or that is important to them, it is usually not because people don't respect their rights but is usually down to lack of staff or other support or having no transport.

*Summary from a submission from a small self advocacy group*<sup>105</sup>

79. We received a good deal of evidence from people with learning disabilities about their experiences of accessing, or trying to access, a whole range of services. On further and continuing education opportunities we heard concerns about restricted provision for some groups, and the lack of progression available.<sup>106</sup> As People First Scotland said: "Most people are sick of 'life-skills' type courses and want to study something that gives them a better chance of getting a job."<sup>107</sup> People also told us about problems they had with transport to college and classes, for example:

we are entitled to free bus passes, but we can't use them until after 9.30 am and a lot of our college courses start at 9.00am which is a problem. Also, if we have electric wheelchairs we are unable to use the public buses even the new low liner ones.<sup>108</sup>

80. We received so much evidence about people's, often negative, experiences of trying to access healthcare, which we consider in Chapter 5. In addition, a number of witnesses drew our attention to the particular difficulties confronting people with learning disabilities in trying to access dentistry services,<sup>109</sup> and in receiving appropriate optical care.<sup>110</sup>

81. A number of witnesses told us about problems in connection with welfare benefits, including problems if they were contemplating starting a job, and, more generally, the lack of easy to understand information and advice available.<sup>111</sup> For example:

The benefits system is hard to understand. There is a lot of jargon and the forms are hard to fill in.<sup>112</sup>

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<sup>105</sup> Annex 2, para 6.

<sup>106</sup> Ev 53, 94, 222, 299, 304, 310, 377.

<sup>107</sup> Ev 327.

<sup>108</sup> Ev 122.

<sup>109</sup> Ev 194, 359, 391.

<sup>110</sup> Ev 373.

<sup>111</sup> Ev 49, 50, 163.

<sup>112</sup> Ev 327.

## Access and choice in housing

I feel so angry, I've got no choice. I want to move, I feel like I'm ready to move. If I said anything to the staff here, they'd say, "no chance", they'd say, "no way".

I said to Mum and Dad I want to leave home. But they said no. They said I can't cook and I can't clean so I can't be on my own.<sup>113</sup>

82. We received evidence about a range of problems here, including lack of choice and control over where people lived and who they lived with,<sup>114</sup> problems over housing benefit, especially where people needed 24 hour support,<sup>115</sup> little security of tenure,<sup>116</sup> and being prevented by staff or family members from moving on to a new place.<sup>117</sup> Some people felt they were inappropriately constrained where they lived: "how many non-disabled people would be punished (not allowed out) if they left a mortgaged or rented home untidy?";<sup>118</sup> others felt more positive about their housing and support experiences:

KeyRing is a housing trust that has worked well for some of us. It is good because they don't interfere if you don't want them to, you can have as much or as little help as you want. This lets you build up your independence and you still know that support is there when you need it.<sup>119</sup>

83. We met members of a KeyRing housing network during the course of our inquiry. They told us how important living on their own in the community was to them, they each needed different levels of support to achieve this. KeyRing staff recognised that theirs was not the only good example of housing support, but they were concerned that local authorities sometimes were too cautious in their approach to enabling adults with learning disabilities to live in the community and that limited resources and suitable housing stock were often cited as barriers to allocating suitable support for people with learning disabilities.<sup>120</sup>

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<sup>113</sup> Submission by Dr Alex McGloughlin, School of Social Sciences, Nottingham Trent University, 16 May 2007, enclosing research findings. Available from Parliamentary Archives.

<sup>114</sup> Ev 50, 57, 58, 328.

<sup>115</sup> Ev 52, 110.

<sup>116</sup> Ev 359.

<sup>117</sup> Ev 121.

<sup>118</sup> Ev 382.

<sup>119</sup> Ev 153.

<sup>120</sup> Committee Visit to Lewisham, Meeting with members of South London Keyring Housing and Support networks, 17 October 2007. See also Ev 390 - 392.

## Access to paid employment

We don't feel we have the same chances of getting a job as other people.<sup>121</sup>

You leave special schools without any qualifications and without the skills you need to work<sup>122</sup>

84. We received evidence on the difficulties faced by young people when they left school and wanted to get a job: “they do not receive the same opportunities as their non-disabled peers.”<sup>123</sup> We heard about the benefit problems people faced if they were fortunate enough to get the chance of a paid job. These problems meant people might have to choose not to work at all, or only very reduced hours.<sup>124</sup> We were told that it appeared to be even harder to get a job if you had a learning disability in Northern Ireland.<sup>125</sup>

85. Our visit to Lewisham College School of Supported Learning confirmed these concerns. Both staff and learners told us how difficult it was to access paid employment for people with learning disabilities. These difficulties meant that it was nearly impossible to find work for people with moderate to severe learning disabilities.<sup>126</sup>

## Relationships with friends and family, sexual or other personal relationships

Our carer says we can't kiss (me and my girlfriend). She says ‘we've got to draw the line somewhere’.<sup>127</sup>

86. People told us about their desire for friends and relationships; the difficulties they had in getting out to meet other people (because of lack of support); and the negative attitudes, strictures, lack of opportunities and privacy they confronted, if they wanted to develop close personal relationships or get married. Although we accept the evidence of the Minister for Care Services that the State does not have “a duty to provide people who are lonely with a friend”, we are concerned that in some circumstances, the experiences of people with learning disabilities engage their right to respect for private and family life

<sup>121</sup> Ev 69.

<sup>122</sup> Ev 237.

<sup>123</sup> Ev 334.

<sup>124</sup> Ev 69, 222, 327, 347, 359.

<sup>125</sup> Ev 323.

<sup>126</sup> Committee Visit to Lewisham, 17 October 2007.

<sup>127</sup> Ev 65.

(Article 8 ECHR) and participation in the life of the community, as guaranteed by the UN Disability Rights Convention.<sup>128</sup> For example, witnesses told us:

We are stuck in at home with not many friends. I would like to go to the pub or to bingo.<sup>129</sup>

and:

People treat you funny. Some won't let you have a relationship. People against us getting married.<sup>130</sup>

87. We welcome the Government's recognition in *Valuing People* that:

Good services will help people with learning disabilities develop opportunities to form relationships, including ones of a physical and sexual nature.<sup>131</sup>

**88. We recommend that the Department of Health revisit this issue in their redrafted *Valuing People Now*, in light of the evidence we have received.**

## Participation in decision-making, speaking up and making complaints

[We are].. often treated like children.<sup>132</sup>

89. We asked people how easy it was for them to be involved in making decisions about their lives. Some of our witnesses felt that they did have a say in decisions made: these were largely people who were involved in self-advocacy groups, whose experience had given them more confidence to speak up for themselves.<sup>133</sup> Others thought it was hard to have a say, because not enough responsibility was given to them. Other witnesses told us that far from being enabled to make complaints about their treatment, people with learning disabilities could be excluded from day to day decisions and choices about how they lived their lives:

Most people with learning disabilities are still being told where to live. Most people with learning disabilities are told what to do during the day.<sup>134</sup>

90. Even those who felt they had a say in decision making themselves felt that “people who have more complex needs often do not because people don't know how to communicate

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<sup>128</sup> Ev 49, 50, 56, 58, 67, 184, 222.

<sup>129</sup> Ev 68.

<sup>130</sup> Ev 49.

<sup>131</sup> *Valuing People*, para 7.39.

<sup>132</sup> Ev 50.

<sup>133</sup> Ev 69.

<sup>134</sup> Ev 68.

with them”.<sup>135</sup> Even if people did have a say it did not necessarily mean that the outcome would be what they wanted:

If we receive services sometimes decisions are made because of money not because of what we need.<sup>136</sup>

91. Most people said it was hard to make a complaint, because the system was difficult to understand or because they did not have the confidence to do so. A number of witnesses talked of being too nervous to complain or worried about what would happen to them if they did so: “If we complain we will get into trouble.”<sup>137</sup> Some people felt there was no point complaining because they would not be listened to. “You can tell someone in authority or a parent, but you are not often taken seriously or believed.”<sup>138</sup>

### Participation in the local community

92. A number of witnesses told us that they thought that the lack of support they received was inadequate to allow them to play any part in their local community.<sup>139</sup> We return to this topic in Chapter 8.

### Families and carers

We are unable to go far as there are no disabled toilets in which to attend to his needs. So as a family we are all restricted in the participation in the local community. He is unable to meet with friends or socialise and without us taking him for a local walk or a short drive in his van we would be completely isolated.

*Mother of an adult with learning disabilities on her family’s experiences*<sup>140</sup>

93. It is estimated that there are around 6 million family carers in the UK.<sup>141</sup> Mencap’s report *No Ordinary Life* found that 60% of parents of children and adults with profound and multiple learning disabilities spent more than ten hours a day on basic physical care. 78% of families received either no support at all or less than 2 hours per week.<sup>142</sup> *Valuing People* stressed the important role that family carers play in supporting people with learning disabilities and enabling them to live more fulfilling lives. *Valuing People Now* records the new commitments by Government to improving the circumstances of family

<sup>135</sup> Ev 69.

<sup>136</sup> Ibid.

<sup>137</sup> Submission from Macclesfield Speaking Up Speaking Out Centre. Available from the Parliamentary Archives.

<sup>138</sup> Ev 50.

<sup>139</sup> Annex 2; See also Ev 57.

<sup>140</sup> Annex 2, para 9.

<sup>141</sup> Ev 287.

<sup>142</sup> Mencap, *No ordinary life*, 2001, p.10, cited Ev 204.

carers but notes that 'life for many family carers remains difficult and further action is needed'.<sup>143</sup>

94. We received evidence from a number of witnesses from carers organisations about their experiences of the denial of human rights to their relatives or themselves.<sup>144</sup> Eve Rank and Richard West, two people with learning disabilities who are themselves carers of other people, said:

Many carers with a learning disability can undertake a significant caring role, but many need the right help or support to do so. Without that support people can flounder from lack of information about what to do and where to go for help.<sup>145</sup>

95. They pointed out that being a carer can have a major impact on the life of the carer and their own ability to lead an ordinary life: 'As carers responsibilities increase, many people do not manage to get much of a life outside of the home, and certainly are unable to partake in ordinary community life.' Unable to work (or only able to work reduced hours) because of their caring responsibilities, family carers are often in a poor position financially.<sup>146</sup> But witnesses told us, that 'carers grants and benefits such as council tax relief go unclaimed' because many people who look after a relative with a learning disability do not think of themselves as a 'carer'.<sup>147</sup>

96. The evidence we received from family carers highlighted the concerns felt by them about many of the issues we identify in this report. There was widespread concern about tightening eligibility criteria and the 'postcode lottery' in the provision of support and services; about the introduction of charging for services provided through adult social care, which could mean that families could sometimes no longer afford to continue their use of them; about services focussing on crisis intervention rather than improving people's everyday lives; and about problems with obtaining a Disabled Facilities Grant in order to get adaptations so that an adult with complex needs could have access to a toilet and shower.<sup>148</sup> We heard of family carers who felt that they were invisible to services until there was a crisis at home and of parents being forced to provide all the personal care needed by their relative when they were hospital inpatients, because of the hospital's reluctance to pay for the additional support required.<sup>149</sup> Witnesses told us of the frustrations they experienced in trying to get adequate help for their relative and the difficulties they faced in trying to keep in touch with them if they were moved away from their home community into out of area placements.<sup>150</sup> They pointed out that: 'many families ... act as powerful, long-term advocates for their sons/daughters, but receive little help themselves.'<sup>151</sup> They

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<sup>143</sup> *Valuing People Now*, para 10.1.3.

<sup>144</sup> e.g. Ev 56, 232, 242, 287, 317.

<sup>145</sup> Ev 317.

<sup>146</sup> Ev 287.

<sup>147</sup> Ev 317.

<sup>148</sup> Ev 287.

<sup>149</sup> Committee Visit to HFT Resource Centre, 24 October 2007, discussions with a parent of two adults with learning disabilities.

<sup>150</sup> Ev 245.

<sup>151</sup> Ev 232.

highlighted the fact that if family carers are not adequately supported it will impact on the lives of their disabled sons and daughters and, that if their relative got ill and they got too old to care for them, it would cost public services a lot of money.<sup>152</sup>

97. Although comments are sometimes made about families holding back their relatives with learning disabilities or being ‘over-protective’, the evidence we received suggested that ‘for most people, most of the time, their families are their greatest and most reliable allies.’<sup>153</sup> As the Foundation for People with Learning Disabilities pointed out:

Too often services focus on the disabled person in isolation and fail to take account of the family situation as a whole. Supporting the family can sometimes be the best way of supporting the disabled person to get a better life.<sup>154</sup>

98. Many witnesses expressed concern about continuing poor treatment, isolation and social exclusion and that the experiences of people with learning disabilities in the United Kingdom illustrated a lack of respect for the human rights of adults with learning disabilities.<sup>155</sup> **We are concerned that the experiences communicated to us by adults with learning disabilities, their families and supporters appear to reflect the findings of the last National Survey, that adults with learning disabilities are more likely than other people to suffer from social exclusion, poverty and isolation.**

99. Not every aspect of the lives of adults with learning disabilities fell within the scope of this inquiry. Indeed, some of the evidence we received did not relate to human rights concerns. However, witnesses consistently told us that there were a number of common themes in the treatment of adults with learning disabilities which cut across a range of issues and which were undermining respect for their dignity and human rights:

- the gap between the Government’s policy on the treatment of adults with learning disabilities and the life experiences of many of our witnesses;
- the difficulties experienced by people with learning disabilities in trying to access services and support; and
- the continuing impact of negative attitudes, assumptions and stereotypes around people with a learning disability.

100. We consider how these themes undermine the ability of adults with learning disabilities to secure respect for their human rights; and whether a human rights based approach could lead to change for the better.

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<sup>152</sup> Ibid.

<sup>153</sup> Ev 217.

<sup>154</sup> Ibid.

<sup>155</sup> See for example Ev 298.

## The gap between policy and practice

The white paper *Valuing People* was full of excellent recommendations, many of which have either been paid lip service, or have been ignored completely. There is a feeling amongst professionals that it was a lot of rhetoric without legislative reach to ensure that its recommendations would be put into practice. There is still a huge gap between what was recommended and what actually happens.

*An NHS Clinical Psychologist in Learning Disability Services*<sup>156</sup>

101. Many witnesses expressed their support for *Valuing People*, and for the existing legal framework, including the Human Rights Act and the Disability Equality Duty, but regretted that it has not made much difference on the ground. For example:

Human rights law and disability discrimination law present opportunities to challenge discrimination and inequality, but this has mostly taken place on a piecemeal, case-by-case basis. The lack of respect for the human rights of people with a learning disability is rooted, in large part, in a lack of funding for the services and support which are needed to ensure that they have the same opportunities and choices and a lack of political will to deliver the improvements which the policy framework appears to promise.<sup>157</sup>

and

*Valuing People* was a document that amongst other things states “nothing about us without us”. Unfortunately despite the guidance given in this white paper, in my view, implementation has been patchy and there seems to be a lack of commitment within services to change the way they work.<sup>158</sup>

102. In its evidence, the Department of Health accepted the conclusion of *The Story So Far* that “mainstream policy and delivery areas such as employment, housing and education have still not effectively taken on the *Valuing People* agenda”.<sup>159</sup> The National Co-Director for Learning Disabilities told us that the primary reason there was a gulf between the Government’s policy and what was happening to people with learning disabilities was the lack of “levers” for the implementation of the policy:

The policy has widespread support in the country, but I think it is true to say that if you look at things like the performance framework and other ways that government uses to get people to comply with policy, they are limited. Therefore, we have had to rely significantly on persuading people that they want to make those changes. Obviously things like the Disability Discrimination Act, and in particular, the

<sup>156</sup> Annex 2, para 7.

<sup>157</sup> Ev 136.

<sup>158</sup> Ev 407.

<sup>159</sup> Ev 97.

Disability Equality Duty, add additional new important levers, but I would say that is the major reason.<sup>160</sup>

103. The Minister for Care Services accepted that, although significant progress had been made, work was still necessary to implement the policy effectively.<sup>161</sup> He confirmed that, until now, he had experienced problems promoting the rights of people with learning disabilities, even within his own Department:

Within my own Department, if I am very frank, there has been a struggle to get the NHS to take the needs of people with learning disabilities anywhere near as seriously as they should have done. If you look at the work of the National Director, Rob Grieg, who you have met, he has in some ways been a lone ranger within the Department...Beyond that, in terms of access for people with learning disabilities to mainstream NHS services, there has not been anywhere near the attention that should have been given to the specific needs and experiences of people with learning disabilities.<sup>162</sup>

104. **We are concerned by the evidence that the framework for improving the lives of adults with learning disabilities does not appear to have had much impact in Government departments other than the Department of Health or the wider public sector; and that the impact of *Valuing People* on the experiences of adults with learning disabilities in their dealings with local authorities and individual service providers has been so patchy.**

105. **We were dismayed to hear the Minister for Care Services describe the National Director for Learning Disabilities as a “lone-ranger” on mainstreaming learning disabilities, rights and policy even within the Department of Health. We are extremely concerned that the Department, which has responsibility for cross-Government policy on learning disability, has failed to take seriously access to mainstream services for adults with learning disabilities, despite the existence of its statutory duties under the Disability Discrimination Act (as amended), the Disability Equality Duty and the Human Rights Act.**

106. The Minister for Care Services told us that the Government was taking a number of steps to close the gap between rhetoric and reality. He told us that, for the next Comprehensive Spending Review period, the Government had not only agreed the money, but also agreed the performance assessment framework.<sup>163</sup> He said that current funding arrangements had to change, with funding moving away from the NHS to local authorities. He told us that *Valuing People Now* would remind people that:

Some of this is grounded very clearly in law. It is not just about doing the right thing, it is not just about best practice, it is about fulfilling statutory obligations.<sup>164</sup>

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<sup>160</sup> Q 118.

<sup>161</sup> Q 154.

<sup>162</sup> Q 158 (Mr Lewis).

<sup>163</sup> Ibid.

<sup>164</sup> Q163. See also Q164.

107. The Minister told us that *Valuing People Now* would involve Government using the levers that were available at a national level to secure better services locally.

108. **We welcome the Government’s recognition that further work needs to be done to implement policy effectively, so as to support the rights of adults with learning disabilities as individuals. We also welcome the Minister’s frank acknowledgement that more pressure needs to be placed on both central and local Government to deliver the policy of *Valuing People*.**

109. In *The Story So Far*, the National Co-Director explained that some local authorities were happy to treat the policy in *Valuing People* as “optional.”<sup>165</sup> **We are concerned that the National Co-Director for Learning Disabilities and the Government have been searching for “levers” to implement a policy designed to ensure that adults with learning disabilities can live their lives in a way which promotes dignity and respect for their rights. We are particularly concerned that the National Co-Director did not appear to consider that public authorities’ duties under the Human Rights Act would hold much sway. We reiterate our concern that the Department of Health and other Government departments should be proactive in promoting a positive approach to the Human Rights Act and to the Disability Equality Duty. We see the value of using these obligations to support or explain a particular policy choice as a ‘lever’ for implementation. However, this should not undermine the binding nature of these duties.**

## Inability to access services and support

When group members can’t do something they want to or that is important to them, it is usually not because people don’t respect their rights but is usually down to lack of staff or other support.

*A small Bedfordshire self-advocacy group*<sup>166</sup>

110. Many witnesses told us that they believed that the inability of people with learning disabilities to access appropriate services and support was indicative of a fundamental lack of respect for their human rights. In particular, witnesses told us about:

- local authority restrictions on eligibility for support by social services, within the Fair Access to Care criteria (discussed below);
- poor care management and planning; particularly on transition into adulthood (i.e. when responsibility for support moves from children’s services to adult services within local authority social services departments);<sup>167</sup>

<sup>165</sup> *The Story So Far*, Foreword.

<sup>166</sup> Annex 2, para 6.

<sup>167</sup> Ev 53, 74, 76, 94.

- out of area provision of support, away from families and communities, for people with complex and profound learning disabilities;<sup>168</sup>
- difficulties co-ordinating support across local authority boundaries;<sup>169</sup> and
- reluctance on the part of some of local and health authorities, supporters and families to enable individuals to take risks in their daily lives.<sup>170</sup>

## Is it all about the money?

The White Paper *Valuing People* talks about the importance of community presence and participation, but £1.75 per week to spend is not enough to enable anyone to do that.

*Parent and carer of an adult with a learning disability.*<sup>171</sup>

If the Government is serious about stopping human rights abuses against people with learning difficulties, then it will simply cost money. If society decides that ultimately it does not care enough about people with learning difficulties to spend money on us, then society exists as a society where people are left out, marginalised and abused in our midst.

*Andrew Lee, Director of People First (Self-Advocacy)*<sup>172</sup>

111. A significant number of witnesses told us that funding for services and support was the key reason that *Valuing People* was not being implemented effectively. Dame Jo Williams, Mencap, told us that more information was required on the need for services and funding, which they hoped to feed into the Comprehensive Spending Review:

The evidence that we have to date is that the increase in the population of people with learning disabilities is about one per cent per annum. The current investment is not keeping pace with that...We are hearing about cuts in services which are affecting people's lives.<sup>173</sup>

112. The evidence we have received on this issue focused principally on access to social and community care services provided by local authorities. Witnesses raised two issues of concern:

- tightening local authority eligibility criteria undermining *Valuing People* and putting the rights of people with learning disabilities and their carers at risk; and

<sup>168</sup> Ev 114, 160-161, 181.

<sup>169</sup> Ev 392.

<sup>170</sup> Ev 219.

<sup>171</sup> Annex 2, para 7.

<sup>172</sup> Q 17.

<sup>173</sup> Q 13.

- inadequate provision for people who could benefit disproportionately from a low level of support, because of the prioritisation of people with more complex support needs.

113. We asked the National Co-Director for Learning Disabilities how the tightening of local authority eligibility criteria would impact on people with learning disabilities and the implementation of *Valuing People*. He told us:

Certainly, if authorities go down that route, there will be significant numbers of people who have traditionally been in receipt of support, to help them get lives as outlined in *Valuing People*, who will not be getting those services in the future.<sup>174</sup>

114. When making assessments of need and decisions about service provision, councils must act in accordance with *Fair Access to Care* Guidance, issued by the Secretary of State. In setting eligibility criteria, councils must take account of their resources, local expectations and costs and agreements with the NHS. They should also consult users and others. Councils are advised in *Fair Access to Care* that they “should have regard to” their legal obligations under the Sex Discrimination Act 1975, the Disability Discrimination Act, 1995, the Human Rights Act 1998, and the Race Relations (Amendment) Act 2000.

115. Recent figures released by the Commission for Social Care Inspection show that the proportion of councils planning only to support people with substantial or critical needs was likely to rise from 53% to 62%, before the end of 2007.<sup>175</sup>

**116. Difficult questions about allocation of resources may be involved when deciding whether to provide support in specific cases. However, we consider these questions must be answered within the context of the legal obligations of local authorities and other public authorities, to respect the dignity and rights of service users. Local authorities must act in accordance with the Disability Equality Duty.<sup>176</sup>**

117. We previously considered the positive duties of public authorities under the Human Rights Act in our recent report, *The Human Rights of Older People in Healthcare*.<sup>177</sup> The Government has since rejected our recommendation that it should legislate to make explicit that all public authorities, including councils, are under a positive duty to take active steps to protect and respect human rights, where the ECHR imposes a positive obligation so to do. The Government said that such a positive obligation was unnecessary, in the light of the duties of the Equality and Human Rights Commission to encourage public authorities to comply with the Human Rights Act.<sup>178</sup> **We are deeply concerned about the Government’s negative response to our recommendations on the need for an**

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<sup>174</sup> Q 126.

<sup>175</sup> Figures provided following a request by Mencap, published by the Learning Disability Coalition. [http://www.learningdisabilitycoalition.org.uk/news/news\\_9.asp](http://www.learningdisabilitycoalition.org.uk/news/news_9.asp).

<sup>176</sup> The High Court recently ordered Harrow London Borough Council to reconsider a decision to change their eligibility criteria, because they had not shown that they had considered the Disability Equality Duty: *Chavda v Harrow* [2007] EWHC 3064.

<sup>177</sup> Eighteenth Report of Session 2006-07, *The Human Rights of Older People in Healthcare*, HL Paper 156-I, HC 378-I, para 146 – 153.

<sup>178</sup> First Report of Session 2007-08 ‘Government Response to the Committee’s Eighteenth Report of Session 2006-07: the Human Rights of Older People in Healthcare’ HL Paper 5; HC 72.

**express positive human rights duty for public authorities. The creation of a positive duty to respect human rights would help kick-start a change of attitude to the role of the Human Rights Act and to rights more generally. We doubt that, at least in the short term, oversight by the Equality and Human Rights Commission will encourage individual authorities to take a more proactive approach. On the other hand, witnesses to this inquiry, including the Minister for Care Services and the Minister for Disabled People, stressed their view that the potential impact of the Disability Equality Duty will be to change fundamentally the way that public authorities look at disability rights. We remain persuaded that the same is true of positive duties and the Human Rights Act. We reiterate our recommendation that the Government consider the introduction of an express positive duty on public authorities to promote respect for human rights, where the European Convention on Human Rights imposes a positive obligation on the State.**

118. The Minister for Care Services told us he was not persuaded that we were getting the best use of investment in services for adults with learning disabilities.<sup>179</sup>

119. The National Co-Director for Learning Disabilities told us that increasing respect for the rights of adults with learning disabilities was not principally an issue of expenditure.<sup>180</sup> He explained that a more positive approach to the rights of people with learning disabilities could be achieved by changing attitudes towards learning disability (we consider this issue below). We asked a number of our witnesses about how to make improvements, if no more additional resources were available. Suggestions ranged from increasing awareness of the Disability Equality Duty and the Human Rights Act,<sup>181</sup> through better control over care planning and management, to more individualised support with greater flexibility.<sup>182</sup>

120. We asked the Minister about tightening eligibility criteria and the balance which councils were required to strike between cheaper support for those with low support needs and more expensive intervention when their needs became critical. In the latest Comprehensive Spending Review, the Government committed to a process of consultation on a Green Paper on the long-term funding of social care.<sup>183</sup> *Valuing People Now* proposes the transfer of responsibility for learning disabilities from Primary Care Trusts (“PCTs”) to local authorities. Associated budgets will also be transferred. Only specialist learning disability healthcare commissioning will remain with PCTs.<sup>184</sup> Shortly after giving evidence to us, the Minister for Care Services published *Putting People First*, a proposal for individual, or personalised, budgets for the care and support of elderly and younger disabled people, including adults with learning disabilities.<sup>185</sup> This programme has a ring-fenced budget of £520 million which will be distributed between 150 councils in England, over three years.

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<sup>179</sup> Q 171.

<sup>180</sup> Q 129.

<sup>181</sup> Q 62–3.

<sup>182</sup> Q 20.

<sup>183</sup> *Comprehensive Spending Review*, October 2007, para 6.9.

<sup>184</sup> *Valuing People Now*, 16.2.

<sup>185</sup> *Putting People First: a shared vision and commitment to the transformation of adult social care*, Department of Health, 10 December 2007.

121. The recent initiatives by Government to grapple with funding in social care, particularly in relation to learning disabilities, seem like a step in the right direction, although they were announced at a late stage in our inquiry, after we had finished taking evidence. We heard some positive support for the introduction of individual budgets, but have also heard concerns about the adequacy of those budgets and the need for separate funding for independent, effective brokerage.<sup>186</sup> **We strongly recommend that guidance to local councils should remind them that decisions about funding must be taken in a way which is compatible with the Disability Equality Duty and the Human Rights Act. We recommend that the Government rewrite its Guidance, including *Fair Access to Care*, to ensure it provides clear, straightforward and accessible examples of a human rights based approach, explains how social care funding decisions could lead to a breach of Convention rights and sets out how to comply proactively with the Disability Equality Duty.**

### Negative attitudes, assumptions and stereotypes about people with a learning disability

Some people take the mick out of me and I used to get bullied, but I know people know about my learning disabilities ... my girlfriend does not have a learning disability. She gets treated fairly more than me because I have a learning disability. People laugh at her when she is with me, but she just says "he is the same as any one else".

*A person with learning disabilities*<sup>187</sup>

When we are born, our parents are given negative views about our chances in life. They are encouraged to mourn the fact that they have abnormal children, and their disappointment stays with us throughout our lives.

*Andrew Lee, Director, People First (Self-Advocacy)*<sup>188</sup>

122. Witnesses told us that providers of mainstream services and people on the street often had negative attitudes, assumptions and stereotypes about people with learning disabilities which made it difficult for people with learning disabilities to gain respect for their human rights. These attitudes and assumptions could lead directly to the denial of individual rights, for example through bullying or hate crime, or they could underlie decisions by others which marginalised people with learning disabilities and undermined their ability to speak up for their rights. Mencap told us:

Despite welcome changes both to the law and to social attitudes, people with a learning disability are still subject to prejudice and misunderstanding and to

<sup>186</sup> Annex 3, para 25 (Philippa Russell).

<sup>187</sup> Annex 2, para 5.

<sup>188</sup> Q 1.

assumptions that they have little to contribute to society. The experience of prejudice may also discourage people with a learning disability from attempting to play a full role in their community and contribute to their isolation and exclusion.<sup>189</sup>

123. Negative attitudes and assumptions can be a particularly significant problem for certain groups, such as people with complex and profound learning disabilities. For example, the PMLD (Profound and Multiple Learning Disabilities) Network told us:

One of the greatest barriers that people who have profound and multiple learning disabilities face is the negative attitudes of others. Judgements are made about the meaning and quality of people's lives. This can stop people being offered more innovative forms of support, such as individual funding, because some people do not think that they will benefit...But these negative attitudes can also be life-threatening – for example if they result in the denial of medical treatment.<sup>190</sup>

124. Other witnesses confirmed the difficulties they encountered as a result of negative attitudes on the part of professionals and service providers. For example, in seeking access to healthcare (which we consider below, in Chapter 5):

People (in health services) think that because we have a disability they don't need to talk to us and they talk to our carers instead. This isn't fair, we're people too.<sup>191</sup>

125. They also told us how negative attitudes could cause difficulties in the wider community:

People felt that there was a general lack of tolerance within the community. The main barriers to people accessing this very important right to participate fully in their community range from a 'benign' lack of understanding of people with learning disabilities to the more worrying abuse of rights such as intolerance and discrimination.<sup>192</sup>

and

People treat you funny. They won't let you have a relationship. People against us getting married.<sup>193</sup>

and

We have experiences, seen and heard, about lots of bullying happening in the community. People with learning disabilities are often scared to go out. We're often called names or people take the mickey in a really nasty way.<sup>194</sup>

126. Andrew Lee, Director, People First (Self-Advocacy) told us:

<sup>189</sup> Ev 137.

<sup>190</sup> Ev 204.

<sup>191</sup> Ev 69.

<sup>192</sup> Ev 88.

<sup>193</sup> Ev 49.

<sup>194</sup> Ev 69.

One of the most tragic things about the recent abuses in Sutton and Merton was that staff did not even know they were doing anything wrong.<sup>195</sup>

127. **We agree with our witnesses that one of the most distressing and worrying things about the investigation by the Healthcare Commission and CSCI into the treatment of people with learning disabilities in Cornwall was that “many of the staff did not believe and understand that what they were doing was wrong”. This episode provides a most harrowing example of how a lack of awareness of the rights of people with learning disabilities can have a devastating effect, leading to situations where the right to be treated with respect for private life is ignored (Article 8 ECHR), and the rights to life and to be free from inhuman and degrading treatment are endangered (Articles 2 and 3 ECHR).**

128. Some witnesses told us that training for professionals and others on learning disability by people with learning disabilities would be needed to change the situation. For example:

People with learning disabilities should be able to access mainstream services but barriers remain, mostly attitudinal barriers and through a lack of education and training, this looks like being a long time before change will occur. We have commenced this change process by offering user led disability equality training and trying to change attitudes of our local community. By promoting a positive image of people with learning disabilities and placing value on their contribution to society we are helping to adjust mind sets and hopefully commence the trend of people with learning disabilities being fully integrated into their community.<sup>196</sup>

129. The National Co-Director for Learning Disabilities told us that changing attitudes would involve promoting the rights of people with learning disabilities:

Those negative attitudes will often come from people who have only ever experienced people with learning disabilities in a negative, passive role in society...It is only when society sees what people are really capable of that I think we will begin to make some major changes.<sup>197</sup>

130. The British Institute of Human Rights said that the promotion of a human rights based approach could improve the treatment of people with learning disabilities, not only by empowering people with learning disabilities but by promoting change within service providers:

We see the wider potential of human rights ideas and human rights approaches for learning disabled people to claim more power and control over their own lives. In addition to individuals acting to claim their rights, we also see the potential for organisations to behave differently – not only taking steps to avoid the worst human rights breaches but also to fully promote and fulfil the human rights of learning disabled people in a way that enables them to flourish as human beings.<sup>198</sup>

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<sup>195</sup> Q 1.

<sup>196</sup> Ev 51.

<sup>197</sup> Q 129.

<sup>198</sup> Ev 131.

131. We welcome the recognition by the National Co-Director for Learning Disabilities of the importance of educating people, and particularly service providers, to see people with learning disabilities as people with human rights which need to be respected. He told us:

Because society has dehumanised people with learning disabilities for centuries, there is still a significant chunk of society that believes it is okay to treat people with learning disabilities in a different way to which would treat a non-disabled person ... The importance of the human rights approach, is that over time, you will gradually create a culture where people understand that what they were brought up on, [such] attitudes ... [which] are not acceptable in modern society.<sup>199</sup>

132. We welcome the recognition of both the Minister for Care Services and the Minister for Disabled People, that while the Government has a responsibility to ensure public authorities meet their duties to respect the rights of adults with learning disabilities under the Disability Discrimination Act and the Human Rights Act, a move away from negative attitudes and assumptions is required:

What we are doing at every opportunity is highlighting to those who deliver our public services in particular, but also to those in the private sector who deliver jobs and various other services, that they have a responsibility to work with those with a learning disability as individuals and not to categorise them, stereotype them or make assumptions about what they can and cannot do. That is where, I think, the human rights perspective is so powerful.<sup>200</sup>

**133. We agree that taking a human rights based approach to service provision could contribute to reversing negative attitudes, assumptions and stereotypes. We again stress that the Department of Health and the Office for Disability Issues should take a lead in creating a positive approach to the implementation of both the Human Rights Act 1998 and the Disability Equality Duty. However, “taking a human rights based approach” means more than using the appropriate language in policy documents or in statements to parliamentary committees. A proactive and practical approach to the implementation of individual rights for people with learning disabilities is needed to replace the existing culture, which has allowed society to “dehumanise” people with learning disabilities for centuries.**

Helen continued to be distressed and her confusion increased. She was sent to a psychiatric ward, where she behaved in ways very unusual for her, pacing and groaning in pain. As Helen’s behaviour worsened she was sectioned under the Mental Health Act. Helen’s family tried to explain ... they believed that the pain ... was the most likely explanation for her change in behaviour. Doctors informed her family that Helen was “just doing this for attention”.

*Mencap Case Study*<sup>201</sup>

<sup>199</sup> Q 138.

<sup>200</sup> Q 164 (Mrs McGuire).

<sup>201</sup> Ev 139.

134. The evidence that we have received in this inquiry strongly suggests we are failing adults with learning disabilities, by failing to afford adequate respect for their human rights. In the following chapters, we focus on four areas which we consider provide the starkest illustrations of adults with learning disabilities being treated without dignity and respect for their human rights:

- The treatment of adults in health and residential care settings, an area that has already had a significant amount of public attention in the light of high profile cases (Chapter 5);
- The experience of parents with learning disabilities (Chapter 6);
- The treatment of adults with learning disabilities in the criminal justice system (Chapter 7); and
- Barriers to an ordinary life confronting adults with learning disabilities (Chapter 8).

## 5 The treatment of adults with learning disabilities in health and residential care settings

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135. The treatment of adults with learning disabilities by health and social care services has been in the spotlight recently, but for all the wrong reasons. In Chapter 2, we referred to a number of reports by organisations including the inspectorates, the Disability Rights Commission and Mencap. All of these concluded that the treatment of adults with learning disabilities by health and social services had been woefully inadequate. In the twelve months preceding our inquiry, no less than five key reports were published detailing abusive, neglectful or discriminatory practice in health and residential care settings. In the light of these reports there has been, and continues to be, considerable focus on investigating and improving practice. This includes the investigation of the six deaths highlighted in Mencap’s Report *Death by Indifference*, by the Health Ombudsman; the recently completed Healthcare Commission Audit; and the ongoing independent inquiry instigated by the Department of Health.<sup>202</sup>

136. Although we have heard of examples of good practice<sup>203</sup> during the course of this inquiry, we have received a considerable volume of evidence which demonstrates that adults with learning disabilities continue to have difficulties accessing good quality healthcare where they are treated as individuals, with respect for their dignity and human rights. **We are concerned, but not surprised, that the evidence we received shows that people with learning disabilities face similar problems in healthcare as older people,**<sup>204</sup> including:

- **Malnutrition and dehydration (Articles 2, 3 and 8 ECHR):**<sup>205</sup>

Two middle managers have been trying for over 8 years to get a “dysphagia” service (eating and drinking) for people with high support needs...This group of people have problems with swallowing and so the position they sit in and their nutrition intake as well as thickness of food/fluids, have to be taught to medical professionals providing care for them. In this PCT (as I am sure is the case in other PCTs as well) this service is only provided if the person is an inpatient in acute services<sup>206</sup>

- **Abusive and degrading treatment (Articles 2, 3 and 8 ECHR):**<sup>207</sup>

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<sup>202</sup> We consider the terms of reference of each of these separate inquiries, above, in Chapter 2. See also Ev 179 (Healthcare Commission); Ev 103 (Supplementary Evidence, Department of Health, Independent Inquiry).

<sup>203</sup> e.g. Ev 177 (Mersey Care NHS Trust); Ev 72 (Cheshire and Wirral Partnership Trust); Ev 381.

<sup>204</sup> Eighteenth Report of Session 2006-07, *The Human Rights of Older People in Healthcare*, HL Paper 156-I, HC 378-I, paras 11 – 57.

<sup>205</sup> Ev 234.

<sup>206</sup> Ibid.

<sup>207</sup> Ev 138; 212, para 14; 226; See also, the conclusions of the Cornwall Healthcare Commission Report and the Joint Healthcare Commission and CSCI Report on Sutton and Merton.

B, a young man with Down's syndrome and Autistic Spectrum Disorder was locked in a day centre minibus overnight in a garage. There is a real possibility that his incarceration was part of a sexual assault. One week later, four male members of staff at his day centre broke his foot whilst trying physically to force him onto a minibus.<sup>208</sup>

- **Neglect or carelessness by health and social care services (Articles 2, 3 and 8 ECHR):**<sup>209</sup>

Her relatives visited after the operation and found Susie lying on her back, eyes open but not saying a word. Usually, she was talkative and lively, and worried, they went to ask the Sister why she couldn't talk. The Sister glanced at the notes and commented 'well, she can't talk can she, if she has a learning disability?' Susie was re-examined and found to have had a minor stroke.<sup>210</sup>

- **Lack of privacy in health and social care settings (Article 8 ECHR):**<sup>211</sup>

I clean my room, when I get home they've done it all again. Why should I do it if they want to do it again? I have a street door key but I can't lock my room door.<sup>212</sup>

- **Lack of dignity in respect of personal care needs (Article 8 ECHR):**<sup>213</sup>

They want me to bath twice a day, the water is often cold.<sup>214</sup>

- **Inappropriate use of restraint and/or medication (Article 8 ECHR):**<sup>215</sup>

We have also worked with many people with a learning disability who are being inappropriately restrained through mechanical and chemical and physical restraints. Despite guidance which sets out procedures and best practice for the decision making and use of restraint we have found a worrying amount of extremely poor practice in this area. We have also found that a restraint is often used as a way of managing low staffing levels and as a first response rather than as a carefully assessed last resort.<sup>216</sup>

Diana, who has a visual impairment and scoliosis, kept colliding with people and furniture and falling, resulting in injuries. The staffing levels at her home were not sufficient to support her when walking round her home so she was strapped into her wheelchair.<sup>217</sup>

<sup>208</sup> Ev 227.

<sup>209</sup> Ev 212, para 16; 227–28.

<sup>210</sup> Ev 295, para 7 (iii); 304, part 1, (Leigh Day & Co Solicitors).

<sup>211</sup> Ev 49, 51, 65, 213, para 16, Ev 381.

<sup>212</sup> Ev 381.

<sup>213</sup> Ev 213, para 16; Ev 227, Case Study 4; Ev 381.

<sup>214</sup> Ev 381, page 2.

<sup>215</sup> Ev 245, 338, paras 8–9.

<sup>216</sup> Ev 338, para 9.

<sup>217</sup> Ev 338, paras 8–9.

K a middle-aged woman with Down's syndrome threw a cup at a wall in her care home on the first anniversary of her mother's death. [...] Instead of trying to find out why she had thrown a cup, the woman was prescribed anti-psychotic medication.<sup>218</sup>

- **Problems with communication, particularly where patients have complex or profound learning disabilities (Article 8 ECHR):**<sup>219</sup>

Staff on the ward may not understand the communication system used by a learning disabled patient (which could be verbal, a recognised sign language such as Makaton or sounds, signs and gestures idiosyncratic to the patient). They may misinterpret or even ignore what the learning disabled patient is trying to communicate.<sup>220</sup>

- **Negative, patronising and infantilising attitudes towards people with learning disabilities (Article 8 ECHR):**<sup>221</sup>

Manny suffered from arthritis in his hands and was in constant pain. His GP refused to prescribe medication on the grounds that "he wouldn't understand" because he has Downs Syndrome.<sup>222</sup>

- **Discriminatory treatment of adults with learning disabilities in access to mainstream services on grounds related to their disability (Articles 2, 3, 8 and 14 ECHR):**<sup>223</sup>

The GP refused to refer Andy to a neurologist for further investigations to clarify the diagnosis on the basis that any further investigations might cause Andy distress and that it was unlikely that any treatment would be offered due to his learning disability and associated behavioural issues, which would make it difficult for him to tolerate any surgery.<sup>224</sup>

- **Fear and difficulties in making complaints (Article 8 ECHR):**<sup>225</sup>

Someone made a complaint about the manager, I got the blame. They excluded me and said things like 'go into your room and eat your breakfast'<sup>226</sup>

137. For many people with learning disabilities, but especially those with more profound or complex needs, challenging behaviour, or communication difficulties, problems accessing appropriate treatment in health care can be exacerbated by the lack of personal support available to them if they are admitted to hospital. Witnesses have told us that confusion over responsibility for continued funding (i.e. whether responsibility lies with the hospital

<sup>218</sup> Ev 227, Case Study 7.

<sup>219</sup> Ev 304.

<sup>220</sup> Ev 304.

<sup>221</sup> Ev 49, 327, para 1; Ev 339, para 12.

<sup>222</sup> Ev 339, Case Study 8.

<sup>223</sup> Ev 227, 213, 327, 339, paras 10–11; Ev 377, para 1.

<sup>224</sup> Ev 339, Case Study 5.

<sup>225</sup> Ev 381.

<sup>226</sup> Ibid.

and the PCT or with the local authority), can lead to a person in hospital being denied the support they require in order to meet their needs: for example, understanding basic elements of their treatment; participating in decisions relating to their care; being able to eat and drink without medical complications (where an individual has particular dietary or feeding needs with which they need assistance); or the ability to communicate levels of pain and discomfort to medical staff.<sup>227</sup> Families continue to report that:

[H]ealth professionals ignore their expertise and ...unreasonable expectations are placed on them to provide personal care for disabled relatives who are admitted to hospital.<sup>228</sup>

138. We are extremely concerned that adults with learning disabilities undergo degrading experiences in health and residential care settings, which closely mirror the experiences of older people, on which we reported in August 2007. This implies that poor treatment and neglect of some of the most vulnerable people in our society, at the times when they are ill, in need of care and support, and most dependent on others to secure their most basic and fundamental rights, is endemic. Treatment involving abuse, neglect or carelessness of the kind uncovered by the Healthcare Commission and the Commission for Social Care Inspection in Cornwall and Sutton and Merton and by Mencap in *Death by Indifference* involves serious and severe human rights breaches. The task of securing the dignity and self-respect of this vulnerable group, which is central to the fulfilment of their human rights, is the responsibility of us all. The creation of a more positive human rights culture in service provision is vital to securing respect for adults with learning disability in need of health and social care services.

### Abuse, neglect and careless treatment of adults with learning disabilities

In the end, Tom spent 96 days in an NHS psychiatric assessment unit. His parents think that this was because there was nowhere else for him to go ... during this time, when he was not in an environment where he was supported by people with the right skills, his health was deteriorating. Tom was eventually diagnosed with a number of serious conditions but it was too late ... and he died a short while after his 20th birthday.

*PMLD Network, "Tom's Transition Story"*<sup>229</sup>

139. The Department of Health was "shocked and saddened" to learn of the deaths of the six individuals in *Death by Indifference*, particularly in light of the disturbing events in Cornwall and at Sutton and Merton.<sup>230</sup> In addition to the announcement of the independent inquiry into healthcare for people with learning disabilities, the Department of Health told us that progress on this issue would be made when *Valuing People* was

<sup>227</sup> Ev 378.

<sup>228</sup> Ev 214, para 25.

<sup>229</sup> Ev 203.

<sup>230</sup> Ev 97.

updated, in *Valuing People Now*.<sup>231</sup> The Department explained that further protection would be provided through the reform of the existing vetting and barring procedures for work with vulnerable adults, provided in the Safeguarding Vulnerable Groups Act 2006, and through the introduction of independent mental capacity advocates under the Mental Capacity Act 2005. The Department told us that its framework project with the British Institute of Human Rights, *Human Rights in Healthcare – A Framework for Local Action*, would “assist frontline organisations to ensure that rights are made a reality.”<sup>232</sup>

140. Our witnesses agreed that a number of changes would help ensure that human rights are made a reality. These included empowering people with learning disabilities through promoting greater access to independent advocacy and information about rights; and by providing more training in learning disability, in human rights and in disability equality for professionals and others who work with adults with learning disabilities, with more involvement of people with learning disabilities in the delivery of such training. Witnesses told us that “a firm commitment was needed from government to embed the principles of the [Human Rights] Act in all aspects of public policy” and to promote “better public understanding of the intention behind the Act and its application to public services” (Healthcare Commission).<sup>233</sup>

141. The Cheshire and Wirral Partnership NHS Trust Learning Disabilities Division told us that “further guidance for PCTs” is required “around the rights of people with learning disabilities”. It called for investment in compulsory basic training, education and support for those working in primary and secondary care on “learning disabilities, human rights and consent to treatment”.<sup>234</sup>

**142. We made a series of recommendations on how to meet these concerns, in our Report on the *Human Rights of Older People in Healthcare*. In the light of the evidence that human rights problems extend beyond older people to a broad range of vulnerable people, we are extremely concerned that the Department of Health has offered few concrete commitments in its response to our previous recommendations on the implementation of a human rights based approach in the NHS.**<sup>235</sup>

143. We propose specific recommendations on the Human Rights in Healthcare project, the role of the National Minimum Standards for health and social care; the health and social care inspectorates (and the new merged health and social care regulator, the Care Quality Commission), health inequalities, and access to specialist, primary and acute services, below.

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<sup>231</sup> Ev 97.

<sup>232</sup> Ev 98.

<sup>233</sup> Ev 83, para 5.2.

<sup>234</sup> Ev 78.

<sup>235</sup> First Report of Session 2007-08 *Government Response to the Committee's Eighteenth Report of Session 2006-07: the Human Rights of Older People in Healthcare* HL Paper 5, HC 72.

### *Human rights in healthcare: A human rights based approach*

144. The Committee heard from Mersey Care NHS Trust, one of the NHS organisations taking part in the Human Rights in Healthcare project. This project specifically focuses on in-patient services for people with learning disabilities. Mersey Care explained that they:

have tried to implement human rights since April 2001 across the whole Trust, not just in learning disabilities, because we think that it is a set of values and principles that are quite a powerful lever for change. We have taken the view that service users and carers across the whole of our Trust, including people with learning disabilities have the right to be involved in decisions that affect them, and that is absolutely everything that we do, so that for example, we involve service users and carers across the whole Trust in appointing our staff, giving people the right to say about the people who come into our homes and their lives, and that includes people with learning disabilities.<sup>236</sup>

145. During the pilot, Mersey Care has focused on the development of a questionnaire for people with learning disabilities using in-patient services. This collects the experiences of service users to assess the extent to which their human rights have been respected and protected. They hope that lessons from this project can be applied to Trust strategy and decision making. During 2007, the Trust's Board committed themselves to the development of a "comprehensive human rights strategy". We asked BIHR and Mersey Care to explain how the project would make a difference for people with learning disabilities. Ms Anne Lofthouse, Lead Officer for Service User and Carer Involvement in Learning Disabilities, Mersey Care NHS Trust, told us that the Trust would be using their initial work to develop an action plan. This would be integrated into all of their work with people with learning disabilities.<sup>237</sup> She explained that the Trust would use the principles of fairness, respect, equality, dignity and autonomy ("the FREDA principles") in its work. Ms Sonya Sceats, Policy Officer at BIHR, explained:

I think FREDA is a very nice concept, in a way. It is an attempt to translate into core principles what the Human Rights Act was always designed to achieve but it is the statutory force behind those principles which give service providers, for example, the confidence that assert for example that if someone is not being treated with respect ...<sup>238</sup>

It is a very important lever ...<sup>239</sup>

146. We are impressed with the commitment of Mersey Care in developing a human rights based approach to their work. This is the kind of institutional respect for human rights for which we have been calling. However, the way in which these pilots are presented implies that embedding human rights is regarded as an exercise in best practice rather than a requirement under the HRA. **While we agree that the HRA is an important 'lever for**

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<sup>236</sup> Q 47.

<sup>237</sup> Q 54.

<sup>238</sup> Q 59.

<sup>239</sup> Q 61.

change’, care must be taken when using such descriptions to ensure that the legal obligations of the Human Rights Act are not undermined or misunderstood.

147. We asked Mersey Care to tell us how they thought the good practice, developed from the Human Rights in Healthcare project, might be spread more widely. Ms Lindsey Dyer, Director, Service Users and Carers of Mersey Care NHS Trust, called for the rights-based approach Mersey Care is piloting to be mainstreamed within the NHS, preferably as part of a new ‘constitution’ for the NHS.<sup>240</sup> **We welcome confirmation by the Department of Health that an independent evaluator has been appointed for its Human Rights in Healthcare project.<sup>241</sup> It is disappointing that the report of the independent evaluator will not be available until Autumn 2008, which will be almost eight years after the HRA was introduced. Nonetheless, we recommend that the findings of the evaluation are published and disseminated widely within the Department of Health (including to Strategic Health Authorities, PCTs and providers of health and social services) and across Government.**

148. Despite our view that the Human Rights in Healthcare project has potential, we are concerned that the Department of Health may see this exercise as a panacea that will lead to a positive culture of respect for dignity and human rights in service provision. In our view, this is only one of a range of initiatives that is needed in order to achieve this aim. We recommend that the Department of Health should use the sixtieth anniversary of the NHS to gain maximum exposure for its positive commitment to ensure that “Human rights are at the centre of the values of the health and social care system in this country”.<sup>242</sup> We consider that the adoption of a clear strategy on human rights in policy making by the Department of Health would set a positive example on the type of culture change which will be necessary to ensure that human rights are really at the heart of service delivery.

### *The role of the health and social care inspectorates*

149. The Healthcare Commission told us that it believed that the Human Rights Act has the potential to provide “a cohesive framework for improving the care of people with learning disabilities” and that “the adoption of a human rights based approach would drive significant improvements in care and in the relationships people with learning disabilities have with service providers”.<sup>243</sup> Both the Healthcare Commission and the Commission for Social Care Inspection (“CSCI”) have told us that the National Minimum Standards for health and social care are key to the protection of the rights of adults with learning disabilities. CSCI told us that: “despite being HRA compliant, the National Minimum Standards do not always capture what matters to most people”.<sup>244</sup> The Healthcare Commission told us that one way of promoting a human rights based approach to healthcare, would be to provide more explicit links between the National Minimum

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<sup>240</sup> Q 79.

<sup>241</sup> Ev 405.

<sup>242</sup> Ev 96.

<sup>243</sup> Ev 188, para 5.

<sup>244</sup> Ev 319, para 12.

Standards for health and social care and the Convention rights protected by the Human Rights Act.<sup>245</sup>

150. We welcome the positive commitment by the Healthcare Commission and CSCI to a human rights based approach to regulation and inspection. We also welcome the commitment of the Healthcare Commission and CSCI to work together to implement the conclusions of the recent Healthcare Commission Audit.<sup>246</sup> We recommend that the Healthcare Commission and CSCI use this process to promote a positive approach to human rights and to the National Minimum Standards by hospitals and care homes.

151. The Health and Social Care Bill proposes to merge the regulatory and inspection systems for health and social care. The Care Quality Commission will assume the responsibilities currently held by the Healthcare Commission and CSCI in 2009. The Government proposes to merge the National Minimum Standards for health and social care, in registration requirements for registered providers of health and social care. It proposes that “human rights will be an important feature in the requirements, and we expect that they will also feature prominently in the regulator’s criteria”. We will consider these proposals as part of our scrutiny of the Health and Social Care Bill.

### ***Access to specialist, primary and acute healthcare services***

John is an older man with a learning disability. He lives in a care home. He started falling over and his mobility decreased, leaving him confined to a wheelchair. His behaviour is changing, and carers believe he is in pain and want the medical causes of this investigated. But because John has challenging behaviours he cannot undergo a scan unless he is anaesthetised. As it is not normal procedure to anaesthetise for a scan, Doctors are currently refusing to carry one out. John’s condition is deteriorating and no-one is able to say why.

*Mencap Case Study*<sup>247</sup>

152. The findings of the Healthcare Commission Audit describe continuing poor quality service provision and inadequate service commissioning. The Commission concluded, after its widespread audit, that it could not “be sure that the rights of people with learning difficulties are always upheld”.<sup>248</sup> The Audit’s conclusions confirm the evidence that we have received: throughout the NHS, there are widespread failings in respect of services for adults with learning disabilities. **We welcome the early Government commitment in *Valuing People Now* to use the forthcoming NHS Operating Framework to require Strategic Health Authorities, PCTs and Trusts to deliver action plans to address the**

<sup>245</sup> Ev 182-83, para 5.

<sup>246</sup> Ev 321, para 30.

<sup>247</sup> Ev 140.

<sup>248</sup> *A Life Like No Other*, Executive Summary, Page 5.

**shortcomings identified by the Healthcare Commission’s audit of learning disability services.**<sup>249</sup>

153. The DRC Formal Inquiry Panel on Health Inequalities for people with mental health problems and learning disabilities, reconvened in September 2007 to consider progress on their original recommendations in *Equal Treatment: Closing the Gap* (which we considered briefly in Chapter 2) and to update their recommendations for further action. *Equal Treatment: Closing the Gap – One Year On*, concluded that very little action had been taken to implement the Panel’s original recommendations. The Formal Inquiry Panel stressed that a clear lead needs to come from the Department of Health on the implementation of the Disability Discrimination Act and the Disability Equality Duty (and that the Government of the Welsh Assembly should play a similar role in Wales):

In a health service that relies increasingly on action by local bodies and in which the Department of Health provides a policy and oversight role, it is all the more important that the Department uses its influence to the fullest. That is particularly so given that so many of the organisations to whom we have directed recommendations appear to have taken no notice of them at all.<sup>250</sup>

154. The Chair of the Panel said:

The term institutional discrimination does not seem too strong to describe what is happening in some quarters.<sup>251</sup>

155. The Department of Health told us that it acknowledged the “barriers described in the investigation” and that it considered the DRC inquiry to be “a major contribution to the thinking around the issues [which] highlights the scale of the problem”.<sup>252</sup> In September 2007, the National Task Force on Learning Disabilities concluded that the Government’s response to the DRC Inquiry was inadequate and did not give enough detail on how it intended to address the issues raised by that report.<sup>253</sup> The Minister told us that he was planning to take a number of steps to meet the DRC recommendations, but that:

It is really about the Department of Health and the NHS consequently, taking the needs of people with learning disabilities seriously and giving them higher status in the future and, whether you are a GP or a senior manager, knowing that people with learning disabilities require a specific and distinct response and they have the same rights in terms of access to mainstream healthcare as any other citizen, and in terms of provision of specialist services this notion that we have got to move away from the

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<sup>249</sup> *Valuing People Now*, 7.2.13.

<sup>250</sup> *Equal Treatment: Closing the Gap – One Year on: Report of the Reconvened Formal Inquiry Panel of the DRCs Formal Investigation into the inequalities in physical health experienced by people with mental health problems and learning disabilities*, September 2007, Preface. See also Executive Summary, Pages 6 – 9; Report, Page 17, Page 27.

<sup>251</sup> *Ibid*, Preface.

<sup>252</sup> Ev 97.

<sup>253</sup> *Could do better, The Task Force’s report on how much has changed for people with learning disabilities*, National Task Force on Learning Disabilities, Annual Report, 2006-07, 10 September 2007.

medical model, other than in circumstances where people have an illness or a health condition.<sup>254</sup>

156. We welcome the frank acknowledgement by the Minister for Care Services that more needs to be done to ensure that adults with learning disabilities can access health services on an equal basis. We consider that practical steps must be taken to meet the recommendations of the DRC Formal Inquiry, not only by the Department of Health, but by other public bodies, including Strategic Health Authorities, PCTs, and local authorities. We are disappointed that progress on implementing the recommendations by the DRC Formal Inquiry has been slow. We welcome the commitment in *Valuing People Now* that work will continue until “nationally led responses to the DRC recommendations are in place”. We urge the Department of Health to provide visible national leadership on the recommendations of the DRC Formal Inquiry, by taking steps to assess progress on each recommendation and to provide a detailed strategy and timetable for implementation. We support the recommendation of the DRC Formal Inquiry, that this should take place with much greater urgency. We recommend that the Equality and Human Rights Commission continue the work of the DRC on this issue and monitor progress closely over the next year, with a view to taking enforcement action if no progress is made.

157. We welcome the Department of Health announcement of the independent inquiry into the healthcare of people with learning disabilities. We also welcome the Government’s commitment in *Valuing People Now* to consider seriously the recommendations of that inquiry on hospital and acute care. We welcome the Government’s decision to highlight the duties of PCTs and general hospital trusts under the Disability Discrimination Act 1995 (as amended). This includes ensuring that their Disability Equality Schemes address those bodies ability and resources to meet the needs of people with learning disabilities.<sup>255</sup> We regret that such a reminder is necessary.

158. In the light of the evidence gathered in this report, we call on the independent inquiry to adopt a human rights based approach to its work. We trust that it will endorse our call for a positive approach to the implementation of the statutory duties in the Human Rights Act and the Disability Discrimination Act 1995 (as amended). We will follow the progress of this inquiry with interest.

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<sup>254</sup> Q 162.

<sup>255</sup> *Valuing People Now*, para 7.2.9.

## 6 Parenting and family life

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John's son was taken into foster care and John is not allowed to see him often enough. He is only allowed to see him for 2 hours once a month. He feels he is missing out on his son's childhood.

CHANGE<sup>256</sup>

Eighty per cent of parents with a learning disability in our project have had some or all of their children removed into care. Little or no support has been provided for the parents after this traumatic loss and the parents live with a judgment of being bad parents primarily because they have a learning disability.

*Pembrokeshire Advocacy*<sup>257</sup>

159. We received evidence that the children of people with learning disabilities are more likely to be removed from their parents' care than the children of people who don't have learning disabilities.<sup>258</sup> Research suggests that this happens in around 50% of cases involving a parent with a learning disability.<sup>259</sup> The National Survey reported that 7% of the people that took part in the survey were parents, but only 52% of those people were looking after their children.<sup>260</sup>

160. Unless justified as a proportionate and necessary response to a risk to the child, or to others, compulsory removal of a child from the care of its parents poses a significant infringement of the rights of both the child and its parents, to respect for their family life (as protected by Article 8 ECHR). Although the State has a broad margin of discretion in taking individual decisions on the need for child protection measures, the European Court of Human Rights has stressed that decisions to remove a child must take into account the availability of help, such as additional educational support for children, and whether it would be more appropriate to provide additional support to a family rather than remove a child. The fact that a child could be placed in a more beneficial environment for his or her upbringing is not enough on its own to justify compulsory removal from the care of its biological parents. The Court will have regard to the positive obligation on the State to enable the ties between parents and their children to be preserved.<sup>261</sup>

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<sup>256</sup> Ev 152.

<sup>257</sup> Ev 120.

<sup>258</sup> Ev 113 .

<sup>259</sup> Ev 114.

<sup>260</sup> *The National Survey*, Page 71.

<sup>261</sup> *Kutzner v Germany*, [2002] 35 EHRR 25, paras 65 – 82. In this case, the European Court of Human Rights considered the removal of parental responsibility for their daughters from a couple with learning disabilities. In this case, the children were placed in two separate foster homes, despite evidence that that the parents were capable of meeting their childrens' needs with support. Although existing levels of educational support had been inadequate to meet

161. The United Nations Convention on the Rights of the Child confirms that every child has the right not to be separated from its parents, unless separation is necessary to meet that child's best interests (Article 9). In this connection, the Convention on the Rights of the Child provides that the State:

[S]hall render appropriate assistance to parents and legal guardians in the performance of their child-rearing responsibilities (Article 18).

162. The UN Disability Rights Convention, although not yet ratified by the UK, makes similar provision and adds that no separation should take place solely on the basis that the parents of a child have a disability. State Parties to that Convention will have a duty to consider alternative care for the child within a wider family setting (Article 24(3)).

**163. Social Services departments, courts and other public authorities working with parents with learning disabilities and their children are subject to the duty to act compatibly with the right to respect for family life, as guaranteed by Article 8 ECHR. The State has a positive, human rights based obligation to protect children from harm and to promote their development. However, any decision which impinges on the relationship between a parent with learning disabilities and his or her children could have very serious implications for the right to respect for their family life. In such circumstances, particular care must be taken to ensure that any restrictions on the development of ordinary family relationships must not only be in the best interests of the child, but must also be a necessary and proportionate response to the level of risk posed to the child or to its parents through continuing care at home. This assessment must take into account all of the relevant facts of an individual case, including the potential for additional support to meet the needs of the parents and the child.**

**164. The Minister for Care Services told us that “political correctness” should not prevent the removal of a child simply because a parent has learning disabilities. We agree that the assessment of whether a child should or should not remain with its parents is a complex one, requiring the careful consideration of many factors, including the best interests of the child and the rights of the child and its parents. We welcome the Minister’s acknowledgement that, unless justified and proportionate in all the circumstances, removal of a child could pose a significant risk to the rights of the child and its parents to respect for family life.<sup>262</sup>**

165. Unfortunately, we received evidence that decisions about the future placement of children of parents with learning disabilities are regularly taken without adequate information, arrangements or support being put in place to allow parents to demonstrate that they can look after their children satisfactorily. We were told that adult social services and children’s services often did not work well together to ensure that families had the support that they needed. We were also told that:

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the needs of the children, the State had not considered whether greater levels of support could be appropriate. The Court also considered that the parents had very limited opportunities for visitation and that the children had been independently placed with different foster parents. The Court considered that although the State has a wide margin of appreciation in relation to individual decisions on child protection, that in this case, the State had acted in breach of Article 8 ECHR.

<sup>262</sup> Q 215.

- assessments were not accessible and did not test parents' abilities or support needs effectively.<sup>263</sup> For example, the British Institute of Human Rights told us about two learning disabled parents who were told their child would be removed because they could not relate to, or successfully care for, a robot baby provided by the local authority to “test” their parenting skills;<sup>264</sup>
- professionals often had negative or stereotyped attitudes about people with a learning disability and their ability to be parents;<sup>265</sup>
- information about parenting which is routinely given to parents without learning disabilities is not provided in an accessible way to new parents who have a learning disability;<sup>266</sup>
- support which parents with a learning disability may require to help them look after their children satisfactorily may not be available from local authorities, due to the application of increasingly narrow eligibility criteria for support by social services as a result of resource constraints.<sup>267</sup>

## Access to support for parents with learning disabilities and their children

Sue phoned our office a few months ago informing us that her child had been taken away from her and she was not being given any rights to visit. The reason given for taking her child away was that she was not able to look after the child. When asked what support and training she had had to look after her child she said that she did not have any support. She was told it would be very expensive to provide this support.

*Values into Action*<sup>268</sup>

166. A number of witnesses told us that it was unfair to consider whether parents with learning disabilities were capable of looking after their children without first making sure that those parents had access to support designed to meet their needs and those of their family. For example, Shaun Webster from CHANGE told us:

I have been talking to parents with learning disabilities all over the country. Many parents have told us about the injustice and heartbreak they have suffered. They have had their children taken away by Social Services in unjust practices. They told me that when they asked for support, they did not get any until it was too late.<sup>269</sup>

<sup>263</sup> Ev 114-16, 131.

<sup>264</sup> Ev 131.

<sup>265</sup> Ev 150, 314, para 6.

<sup>266</sup> Ev 152.

<sup>267</sup> Ev 150, 314, para 6.

<sup>268</sup> Ev 236.

<sup>269</sup> Q 83.

167. CHANGE told us that:

There should be more support and education for people with learning disabilities about sex, relationships, and parenting. This would mean that people would be more prepared for parenting, and so it would not be so easy for professionals to say their children should be taken away.<sup>270</sup>

168. The Foundation for People with Learning Disabilities said:

The Norah Fry Research Centre undertook a recent study on the experiences of parents with learning disabilities, which confirmed the poor support experienced by many. The findings are echoed in our work with community learning disability teams: members often report on the challenges of working with children and families teams that focus strongly on risk to the child and can be reluctant to invest in support to enable the parent(s) to be ‘good enough’. Tight eligibility criteria can also limit the support community learning disability teams can offer.<sup>271</sup>

169. During the course of our inquiry, the Department for Health and the then Department for Education and Skills published new *Good Practice Guidance on Working with Parents with a Learning Disability*.<sup>272</sup> This guidance is aimed at professionals in health and social care. It provides examples of good practice, with a summary of relevant legislation and policy on how adult and children’s services “should work together to improve support to parents with a learning disability and their children”. **We welcome the acknowledgement in the Government’s *Good Practice Guidance on Working with Parents with a Learning Disability* that people with learning disabilities “have the right to be supported in their parenting role, just as their children have the right to live in a safe and supportive environment.” We also welcome the acknowledgement that while children have the right to be safe from harm, children’s needs are usually best met by support for their parents, to look after them.**

170. The recommendations in the *Good Practice Guidance* are “underpinned by current legislation and statutory guidance for both children’s and adult’s services and by disability discrimination legislation”. We are encouraged that the *Guidance* acknowledges that it is “intended to assist local authorities to fulfil their disability equality duty to promote equality of opportunity for disabled people”. Unfortunately, neither the *Guidance* nor the explanation it provides of the statutory framework and the obligations of local authorities, clarifies either public authorities’ duties to act compatibly with the right to respect for private and family life; or the balance that must be struck to justify any interference with that right (i.e. an explanation of the duty under Section 6, Human Rights Act 1998).<sup>273</sup> The *Guidance* sets out five features of good practice in working with parents with learning disabilities: accessible information and communication; clear and co-ordinated referral and

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<sup>270</sup> Ev 153.

<sup>271</sup> Ev 216, para 34. See also Ev 223.

<sup>272</sup> *Good Practice Guidance on Working with Parents with a Learning Disability*, published 1 June 2007. This document is only available online: [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_075119](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_075119).

<sup>273</sup> Although the *Guidance* refers to the parent’s right to respect for private and family life, it gives no explanation of the scope of that right, or justified and proportionate interferences in the interests of the child. There are no express references to the right of the child to respect for his or her family life.

assessment processes and eligibility criteria; support designed to meet the needs of parents and children based on assessment of their needs and strengths; long-term support if necessary; and access to independent advocacy. **We consider that if the recommendations for good practice in each of these areas were implemented effectively, this could significantly reduce the risk that parents and children would be separated, in breach of the Convention.**

171. Despite the positive approach advocated by the *Good Practice Guidance*, barriers to the effective support of parents with learning disabilities may well remain in place. We are concerned that successful support depends not only on effective dissemination of the *Guidance* by central Government but also its effective implementation by local authorities, NHS Trusts and others. The Working Together with Parents Network told us that they remain deeply concerned that the rights of parents with learning disabilities and their children to a family life, as provided by Article 8 ECHR, will continue to be infringed.

172. They explained:

There are currently no plans from the Department of Health/Department for Education and Skills to run any events to ensure that information on the guidance is well disseminated to professionals who should be implementing it in practice.

173. They were also worried about funding:

We are aware that...at least one of the examples of good practice we cited...has closed because of funding problems. Given current pressures on local authority budgets it seems all too likely that this situation will be replicated elsewhere.<sup>274</sup>

174. We asked the Minister for Care Services and the National Co-Director for Learning Disabilities about the Government's plan to ensure that the *Good Practice Guidance* would be implemented effectively. The National Co-Director for Learning Disabilities told us that the *Good Practice Guidance* was initially being disseminated through a series of conferences run by an independent parents network.<sup>275</sup> The Working Together with Parents Network told us that these conferences were heavily oversubscribed.<sup>276</sup> The *Guidance* was also being disseminated through meetings of the *Valuing People* network; and distributed in paper and electronic formats. The National Co-Director for Learning Disabilities accepted that the *Good Practice Guidance* had been principally disseminated thus far to professionals working in adult services and that more work needed to be done to ensure that staff in children's services were aware of its recommendations.<sup>277</sup> The Minister for Care Services drew attention to the discussion of this issue in *Valuing People Now*, which we comment on, below<sup>278</sup>

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<sup>274</sup> Ev 315-16.

<sup>275</sup> Q 139.

<sup>276</sup> Ev 315-16.

<sup>277</sup> Q 139.

<sup>278</sup> Q 271

## Access to information for parents with learning disabilities

There are no special ante natal classes or accessible information on having a baby.

*Inclusion North Steering Group*<sup>279</sup>

175. Some witnesses focused specifically on the lack of easy to understand information for people with a learning disability who had had, or were about to have, a baby. Witnesses were concerned that information that would otherwise be available to new parents was not routinely provided in an accessible format for parents with a learning disability, as should be the case under the Disability Discrimination Act. CHANGE told us that they produced a book for parents with learning disabilities, in Easy Read, called *You and your baby*, which had been funded by the Government. They had been told by the Department of Health that once the current print run has been distributed, no more copies will be printed. CHANGE also produce books for parents with learning disabilities who have children aged 1-5 years. Although they received government funding to produce the books they “get no support with how to distribute them for free”.<sup>280</sup> We asked the Minister for Disabled People whether the Department of Health, a local PCT or other public authority would be in breach of its duty to make reasonable adjustments under the Disability Discrimination Act, if it failed to provide parents with learning disabilities with accessible information like the usual parenting material that was routinely distributed to non-disabled parents. We welcome the Minister’s recognition that:

[U]nder the Disability Discrimination Act the provision of information such as this is likely to be seen as a service to the public. The duty is to make reasonable adjustments to enable disabled people to access that information...A reasonable adjustment might be the provision of an Easy Read version, but equally it might be somebody providing the information verbally.<sup>281</sup>

176. We welcome the Government’s commitment in *Valuing People Now* to more appropriate support to parents with learning disabilities over the next three years. Nationally, it proposes:

- to take action to ensure that the Government’s programmes of work aimed at supporting parents generally, and those aimed at groups of parents having particular difficulties, for example, the Family Pathfinders initiative, are inclusive of parents with learning disabilities;
- to ensure that information aimed at parents by the Department of Health and the Department for Children, Families and Schools is available in accessible formats;
- that the Care Services Improvement Partnership will work with the relevant Government departments and the Working Together [With Parents] Network to

<sup>279</sup> Ev 119.

<sup>280</sup> Ev 152.

<sup>281</sup> Ev 404.

disseminate the *Good Practice Guidance*, particularly to children's social care services and mainstream health services;

- locally, it proposes that adult and children's services, supported by local learning disability partnerships, will work together to implement the *Good Practice Guidance*.<sup>282</sup>

177. We welcome the recognition in *Valuing People Now* of the need to do more to improve support to parents with learning disabilities and their children. But we remain concerned that there are few concrete proposals for action or measurable targets regarding improving support to parents with learning disabilities and their children in that document.

178. Although we welcome the commitment of the Department of Health and the Department for Children, Schools and Families to the provision of information in an accessible way, the Minister for Disabled People has accepted that it is likely that this commitment is no more than the Disability Discrimination Act already requires of those Departments.

179. While we recognise the potential of the *Good Practice Guidance* to improve support for parents with learning disabilities and their children, its effectiveness will depend entirely on positive dissemination and widespread implementation by local authority adults' and children's services, NHS Trusts and others. We are disappointed that the active dissemination of this important Guidance has so far relied principally upon the work of an independent parenting network, albeit supported by the Office of the National Director and his colleagues. We welcome the proposed involvement of the Care Services Improvement Partnership in further dissemination of the Guidance. We call upon the Government to set out clearly its proposals for ensuring that all local authority social services departments, including children's services and NHS Trusts are aware of the *Good Practice Guidance* and, importantly, that relevant professionals have training in its effective implementation.

180. We note that although *Valuing People Now* refers to the need for independent advocacy for parents with learning disabilities, it makes no proposals for action to ensure and increase the availability of such provision. We call upon the Government to take action on this issue in our discussion of advocacy in Chapter 8 below.

181. We consider that the proposals for monitoring progress in *Valuing People Now* are particularly weak and lack precision. Public authorities have binding duties under the Disability Discrimination Act and the Human Rights Act to provide services without discrimination, to implement effectively their positive duties to disabled people, and to uphold the rights of parents with learning disabilities and their children to respect for their private life. In the light of these duties, we recommend that the Department of Health requires Learning Disability Partnership Boards to report annually on local commissioning of services to support parents with learning disabilities; and ensures that data is collected locally on the numbers of parents with learning disabilities

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<sup>282</sup> *Valuing People Now*, Section 12.4.

**supported by community teams for people with learning disabilities, and the numbers of their children taken into care, each year.**

## 7 Treatment of people with learning disabilities in the criminal justice system

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182. In our original call for evidence, we did not specifically ask for evidence of what people with learning disabilities thought about the criminal justice system. In national surveys of people's fears and concerns, policing and criminal justice consistently ranks highly. However, the evidence we received during the course of this inquiry raises serious concerns. The problems in relation to the investigation and prevention of ill-treatment of people with learning disabilities, such as abuse, bullying and harassment, when that treatment involves criminal behaviour, are particularly acute. The State has a positive obligation to investigate, and in some cases, prosecute, individuals who have committed criminal offences, particularly those which involve assaults on people and endanger life and physical integrity.<sup>283</sup>

183. Some witnesses told us that adults with learning disabilities are not treated fairly when they are accused, or convicted, of criminal offences. We recognise the Government has a responsibility to protect the public from criminal behaviour. However, as we have consistently emphasised, the Government also has obligations to protect the rights of those people accused, or convicted of, having committed a crime, both under the common law and under the rights to liberty and to a fair hearing, as guaranteed by Articles 5 and 6 of the ECHR. Particular care must be given to the rights of vulnerable defendants or prisoners, including children, those with mental health issues, or with learning disabilities.

184. In response to this evidence, we wrote to the Ministry of Justice, the Home Office, the Director of Public Prosecutions, the Association of Chief Police Officers ("ACPO"), the Metropolitan Police Commissioner, the Director General of the Prison Service and the Director of the Probation Service.<sup>284</sup> We have, so far, received responses only from the Director of Public Prosecutions,<sup>285</sup> ACPO<sup>286</sup> and the Director of the Probation Service<sup>287</sup>. Although we have some serious human rights concerns about criminal justice issues, we have not had the opportunity to discuss these with Government. We may wish to return to these matters in a future inquiry.

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<sup>283</sup> *X and Y v Netherlands* [1986] 8 EHRR 235.

<sup>284</sup> Ev 384; Letter from the Chair to the Rt Hon Jacqui Smith, Home Secretary. See also: Ev 406, letter from the Chair to Director General of the Prison Service, Mr Paul Wheatley.

<sup>285</sup> Ev 392.

<sup>286</sup> Ev 402.

<sup>287</sup> Ev 405.

## Victims of Crime

I answered a phone call from [the police force local to my son's school], who told me they suspected [my son] and two other pupils at [his school], had been sexually assaulted, and that they were passing the case onto [our local police] – which they did. Although [our local police] were sympathetic they categorically refused to interview [my son]. This was because he had mental health issues and extreme challenging behaviour.

*Mother of an adult with learning disabilities*<sup>288</sup>

Adults with learning disabilities have a higher risk of being the victims of crime and abuse, and face greater hurdles to achieving justice, than the general population. They are often targeted because of their perceived vulnerability and are sometimes targeted specifically because of their learning disabilities. Yet, adults with learning disabilities are less likely to report the crime and abuse they have suffered and are less likely to seek help. For many, the violation of their human rights is seen as a normal part of their everyday lives.

*Respond, Ann Craft Trust and VOICE*<sup>289</sup>

185. We considered in Chapter 3 the devastating effect that negative attitudes, assumptions and stereotypes can have on the lives of people with learning disabilities. In Chapter 2, we considered briefly some of the recent, shocking cases of crimes involving adults with learning disabilities. The evidence we have received suggests that people with learning disabilities may be vulnerable to a range of ill-treatment, ranging from verbal abuse, through harassment and bullying to neglect, sexual or financial exploitation, to physical assaults.<sup>290</sup> For example:

We have experienced, seen and heard about lots of bullying happening in the community. People with learning disabilities are often scared to go out.<sup>291</sup>

People said that they were restricted in their ability to go out and enjoy their local community, because of the name-calling and hate crime. They urgently wanted something to be done about this problem. They also felt that it was important to use the words 'hate crime' rather than bullying, since the latter plays down the importance of what people experience.<sup>292</sup>

<sup>288</sup> Annex 2, para 5.

<sup>289</sup> Ev 248, para 1.1.

<sup>290</sup> Ev 80, 87, 91, 93.

<sup>291</sup> Ev 69.

<sup>292</sup> Ev 224.

186. *Valuing People Now* acknowledges that people with learning disabilities are reporting that they do not feel safe in their local communities, because they face crimes targeted at them due to their learning disability.

187. We were told by a number of witnesses that there are three principal issues which cause concern for people with learning disabilities who may be victims of crime:

- firstly, serious crimes against people with learning disabilities are not taken seriously, but are diminished by using the label of “abuse”;
- secondly, people with learning disabilities aren’t able to report crimes easily, or aren’t taken seriously when they do report crimes; and
- thirdly, not enough is being done about disability hate crimes.<sup>293</sup>

### ***Taking crimes against people with learning disabilities seriously***

24 families raised concerns about “accidents” experienced by their sons and daughters at a respite care centre, resulting in bruises, cuts and behaviour changes. However, once the police and CPS were involved the case was dismissed as the witnesses were seen as too unreliable to make the case for the prosecution.

*Mencap Case Study*<sup>294</sup>

There is a risk that sometimes, services including the criminal justice services see someone has a learning disability and think it is their learning disability that has to be dealt with rather than the crime.

*National Co-Director for Learning Disability*<sup>295</sup>

188. Respond, Ann Craft Trust and VOICE told us that incidents involving ill-treatment of people with learning disabilities should not be referred to as “abuse” when in fact they amount to criminal acts:

...the use of the term abuse to refer to crimes devalues the offences and the victims. It is our experience that calling a criminal offence abuse also encourages organisations to believe that these crimes do not need to be reported to the police but can be dealt with by the organisation.<sup>296</sup>

189. This reluctance to treat such incidents as crimes was also highlighted by Mencap:

<sup>293</sup> Ev 247; See also *Valuing People Now*, 12.1.1.2.

<sup>294</sup> Ev 142, Case Study.

<sup>295</sup> Q 144.

<sup>296</sup> EV 248, para 2.1.3.

Too often Protection of Vulnerable Adult (POVA) procedures, or internal disciplinary measures in care services, are used instead of criminal proceedings giving the impression that crimes against people with a learning disability are worthy of less serious action than those committed against other individuals.<sup>297</sup>

190. *Valuing People Now* recognises this is an issue for people with learning disabilities:

Whilst adult protection might be appropriate, people have the same rights as every other citizen to justice through the criminal system.

191. We asked the National Co-Director for Learning Disabilities about these issues. He told us that:

One of the problems is that when people are subject to any type of crime, they often find themselves referred through protection of vulnerable adult procedures which may well be appropriate and should be pursued when they need to be, but often, that is at the expense of them getting legal redress through the criminal justice system.<sup>298</sup>

192. In 2000, the Government published a national framework, *No Secrets*, for local councils with social services responsibilities, local NHS bodies, local police forces and other partners which aimed to develop local multi-agency codes of practice to help prevent and tackle abuse against vulnerable adults.<sup>299</sup> *No Secrets* was drafted before the entry into force of the Human Rights Act, although it aims explicitly to build on the Government's respect for human rights.<sup>300</sup> This guidance states that criminal investigation should take priority over all other lines of inquiry.

193. Our witnesses expressed concern that the current guidance on the protection of vulnerable adults, *No Secrets*, is out of date. It fails to draw an adequate distinction between duties to report suspected criminal behaviour and responsibilities for safeguarding vulnerable adults, when abusive treatment did not amount to a crime.<sup>301</sup> ACPO told us that the police service had "long recognised the limitations in law" for the protection of vulnerable adults.<sup>302</sup>

194. In June 2007, Ivan Lewis MP, Minister for Care Services announced that there would be a review of the effectiveness of *No Secrets*. ACPO told us that they are pushing for the introduction of new legislation which would provide similar protection against abuse for vulnerable adults, including people with learning disabilities.<sup>303</sup> *Valuing People Now* proposes to commit the Government to new guidance on hate crime and learning

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<sup>297</sup> Ev 143; See also Ev 261, para 6.8.

<sup>298</sup> Q 144.

<sup>299</sup> *No Secrets. Guidance on developing and implementing multi-agency policies and procedures to protect vulnerable adults from abuse*, Department of Health, 2000.

<sup>300</sup> *Ibid*, para 1.1.

<sup>301</sup> Ev 263.

<sup>302</sup> Ev 403.

<sup>303</sup> *Ibid*

disability with funding for two voluntary sector initiatives to increase awareness and reporting of crime by people with learning disabilities.<sup>304</sup>

195. **We recognise that not all abuse against adults with learning disability will amount to criminal behaviour. We recognise that in many circumstances, individuals who uncover abuse and criminal behaviour against vulnerable adults will rightly treat the protection of the victim as a priority. Where an individual has been seriously assaulted or where his or her life has been endangered, there is a clear obligation on the State, secured by that individual's ECHR rights, to conduct an effective investigation of the circumstances of the abuse. This includes an obligation to provide for the prosecution of the individual responsible, if appropriate. These important human rights obligations apply to everyone, including people with learning disabilities, unless there are objective reasons why an investigation or a prosecution should not go ahead.**

196. **We recommend that in the review of *No Secrets* and the proposed *Valuing People Now* guidance on crime and people with learning disabilities, the Government provides clear and accessible guidance on protecting people with learning disabilities (and other vulnerable adults) from abuse and ensuring that if a crime is suspected, effective steps are taken to inform and involve the police. We urge the Government to ensure that the relevant criminal justice agencies, including the Association of Chief Police Officers, the Crown Prosecution Service, the Home Office and organisations of and for people with learning disabilities, are closely involved in shaping this guidance.**

197. In our recent report on older people in healthcare, we made a number of recommendations to deal with abuse in a health and social care setting. These included our proposal, that the Government should consider requiring hospitals and care homes to place a duty on health and social care workers to report abuse or suspected abuse. The Government has decided to devise new registration requirements as part of the reform of health and social care. **We are disappointed that the Government has not agreed to create a duty to report abuse, as we previously recommended. We call on the Department of Health, as part of their review of the *No Secrets* Guidance, to reconsider our recommendation that there should be a duty on those working with vulnerable adults, at least within the NHS and in care homes to report suspected abuse.**

### ***Increasing the confidence of people with learning disabilities in the criminal justice system***

198. We are concerned about the extremely low level of confidence that some people with learning disabilities have in the criminal justice system. For example:

- people with learning disabilities sometimes do not know that what is being done to them is a criminal act. Instead, many people with learning disabilities believe that the crime that they experience is simply a normal part of life;<sup>305</sup>
- people with learning disabilities may not know how to report a crime;<sup>306</sup>

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<sup>304</sup> *Valuing People Now*, 12.1.2.2.

<sup>305</sup> Ev 247, Annex 3.

- it can be particularly difficult for people with learning disabilities to raise their concerns if they have communication difficulties;<sup>307</sup>
- it is difficult if the complaint is about the person providing care as a person with learning disabilities may fear the loss of care, accommodation or other support if they make a complaint and/or make a report to the police;<sup>308</sup>
- even if they report a crime, a care provider may not take the issue any further or may (as discussed above) investigate the matter themselves instead of involving the police;<sup>309</sup>
- police can be unhelpful;
- people with learning disabilities are not confident in talking to the police when they have been victims of a crime;<sup>310</sup>
- the police can be reluctant to accept that a crime has been committed if the victim has a learning disability;<sup>311</sup>
- alleged crimes might not be investigated or prosecuted because people with a learning disability, are not considered to be reliable witnesses. This is particularly the case where the person has communication difficulties;<sup>312</sup>
- information is not provided in a format that is accessible to people with learning disabilities and frontline police officers do not receive sufficient training to enable them either to identify someone with a learning disability or know how to meet their needs;<sup>313</sup>
- the police do not always consider using the special measures available under the Youth Justice and Criminal Evidence Act 1999 and may assume that the individual with a learning disability cannot give evidence;<sup>314</sup>
- once a complaint has been made, the Crown Prosecution Service may think that the complainant with learning disabilities will not be able to give credible evidence, or that it will be too stressful for them to do, which may reduce the likelihood of a successful prosecution.<sup>315</sup>

199. Witnesses drew our attention to a number of recent, positive developments, including:

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<sup>306</sup> Ibid.

<sup>307</sup> Ev 247.

<sup>308</sup> Ibid.

<sup>309</sup> Ibid.

<sup>310</sup> Ev 80, 142.

<sup>311</sup> Ev 122, 142.

<sup>312</sup> Ibid.

<sup>313</sup> Annex 3, para 41-3.

<sup>314</sup> Ev 142-144,; 170.

<sup>315</sup> Ev 268, para 9.

- the amendment of the ACPO and Home Office Police Standards Unit Tactical Manual to include disability hate crime;<sup>316</sup>
- adoption of a Crown Prosecution Service Policy on Prosecuting Cases of Disability Hate Crime;<sup>317</sup> and
- the national roll out of the intermediaries programme, as one of the Special Measures open to vulnerable and intimidated witnesses, including adults with learning disabilities, to give their best evidence in court.<sup>318</sup>

**200. People with learning disabilities, in common with the wider population, may have mixed experiences of dealing with the police, the courts and other parts of the criminal justice system. Every part of that system has an obligation to promote equal access to their services for disabled people, including those with learning disabilities, as part of their duties under the Disability Equality Duty.**

### *Hate crimes and learning disability*

201. We received a lot of evidence about “hate crime” against people with learning disability. Witnesses’ concerns principally covered two issues. Firstly, that people with learning disabilities were more likely to suffer crime as a result of their vulnerability and as a result of negative attitudes towards people with learning disabilities. Secondly, that although the law provides for increased sentences in cases where the offender demonstrates hostility based on disability or perceived disability or where a crime is motivated by that hostility,<sup>319</sup> this power is rarely used.<sup>320</sup>

202. In *Valuing People Now*, the Department of Health confirms that “Stopping hate crime against people with learning disabilities is a new part of the *Valuing People* policy”.<sup>321</sup> The Government propose to take action to “address hate crime” and to “help ensure that people feel safe in their local communities”. It is proposed that the Home Office, working with the Department of Health, will produce guidance for the criminal justice system on hate-crime and learning disability. The Home Office will fund voluntary sector projects to help people with learning disabilities protect their personal safety and report crime.<sup>322</sup>

203. Between April and September 2007, we understand that there were 68 prosecutions where section 146 of the Criminal Justice Act played a role.<sup>323</sup> We asked the National Co-Director for Learning Disabilities whether figures were available on crimes aggravated by hostility on the grounds of disability, and particularly on the grounds of learning disability. He told us that “data collection around crime and hate crime does not specifically identify

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<sup>316</sup> Ev 276.

<sup>317</sup> Ev 252, 396 para 55.

<sup>318</sup> Ev 266, 398.

<sup>319</sup> Section 146, Criminal Justice Act 2003.

<sup>320</sup> Section 146, Criminal Justice Act 2003. Ev 247, 250, para 3.

<sup>321</sup> *Valuing People Now*, Chapter 12.

<sup>322</sup> *Valuing People Now*, 12.1.2.

<sup>323</sup> Ev 287, para 7.2.

that a person has a learning disability, they are broader categories than that”.<sup>324</sup> The British Crime Survey does not gather specific information on whether those participating in the survey have learning disabilities, nor does the survey involve residents of care homes.<sup>325</sup>

**204. We welcome the Government’s commitment to meet the concerns of people with learning disabilities about hate crime, in *Valuing People Now*. We welcome the proposal that the Home Office should lead on the production of guidance to address hate crime and to increase the safety of people with learning disabilities in their communities. We recommend that people with learning disabilities, their carers and supporters, ACPO, the Police Federation and the CPS are closely involved in the production of this guidance. We consider that more accurate information would better inform the Government’s policy on this issue. As part of the Government’s commitment to address hate crime and the personal safety of adults with learning disabilities, we recommend that steps be taken to gather more consistent data on the level of crime against people with learning disabilities, either through a survey sponsored by the Home Office, or as part of the British Crime Survey.**

205. ACPO has issued guidance which provides that a hate-crime against a person with a disability, or a “disablist incident”, includes any incident which is perceived by the victim or any other person as “based upon prejudice towards and hatred of the victim because of their disability”<sup>326</sup>

206. The CPS told us that they were taking proactive steps on hate crime and the application of section 146 of the Criminal Justice Act 2003. They explained that their recent guidance on *Prosecuting Cases of Disability Hate Crime* “makes clear their commitment to dealing with this serious and sensitive type of offending”. However, they explained that, although they urge prosecutors to be proactive in seeking evidence of hostility or motivation on the grounds of disability, in order for disability to be considered an aggravating factor in sentencing, section 146 must apply:

Some disabled people may be victims of crime because they are perceived as being vulnerable – easy targets. Where there is no evidence of hostility or motivation and s.146 cannot therefore be applied, prosecutors are none the less reminded that they should consider the culpability of the defendant and the consequences of the victim so that the case can be put before the court in a way that enables it to sentence appropriately.<sup>327</sup>

207. The CPS told us that they were proposing to change their guidance on charging, so as to require the police to refer incidents which fit the ACPO criteria for a hate crime to the CPS. This enables an early discussion about hostility and motivation.<sup>328</sup> They explained that this would allow information about the offence to be identified and steps taken to gather relevant evidence at an early stage.

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<sup>324</sup> Q 146.

<sup>325</sup> Ev 249.

<sup>326</sup> Home Office Police Standards Unit and the Association of Chief Police Officers, *HateCrime: Delivering a Quality Service*, March 2005, para 2.3.7.

<sup>327</sup> Ev 397, para 57.

<sup>328</sup> Ev 397, para 60.

208. We asked the National Co-Director for Learning Disabilities what he thought about the CPS policy. He said that he thought that: “it could have been strengthened if there had been a greater degree of engagement from the CPS with myself and my colleagues when they were writing it. There is more engagement now and we hope to build on what they have done in the future.”<sup>329</sup>

**209. We welcome the recent steps taken by ACPO and the CPS to improve their policy on crimes against victims with disabilities and hate crime, including against adults with learning disabilities. We were disappointed to hear that the CPS had not initially worked closely with the National Co-Director for Learning Disabilities. We recommend that, where any public sector agency is considering a policy which is relevant to disabled people, steps are taken to ensure that people with learning disabilities are specifically considered as part of the policy formulation, and if possible involved in the preparation of that policy. We welcome the proposal by the CPS to amend their charging guidance to ensure that they are involved at an early stage in the investigation of crimes against people with a learning disability where hate crime is suspected. Whilst any decision on prosecution must be based upon the evidence available and should take full account of the rights of the defendant, we consider that this would be a positive development which could increase the confidence of adults with learning disability in the police and the criminal justice system, by ensuring that any element of hostility or prejudice towards them is properly investigated and considered as part of any prosecution.**

## Accused and defendants

If they'd explained things to me, I'd be able to do what they said. I was on bail and I wasn't allowed to go to certain houses, and I went there. I didn't understand it because no-one told me what it was all about. So I went there, got arrested, ended up in the magistrates because I'd breached my bail conditions.

*Member of the Working for Justice Group, Prison Reform Trust*<sup>330</sup>

210. We received evidence from the Prison Reform Trust (“PRT”) on the treatment of people with learning disabilities who are accused of crimes. The PRT told us that it is currently working on a programme, entitled, “No one knows: Offenders with learning difficulties and learning disabilities”, which aims to “effect change by exploring and publicising the experiences of people with learning difficulties and learning disabilities who come into contact with the criminal justice system”. The PRT told us that when people with learning disabilities come into contact with the police and the courts service, they are less likely than people without learning disabilities to receive a fair hearing.<sup>331</sup> This evidence included a number of individual examples of maltreatment by the police of people with learning difficulties or disabilities, including “being ‘roughed up’”; being placed under

<sup>329</sup> Q 145.

<sup>330</sup> Ev 169.

<sup>331</sup> Ev 166-76, Annex 3, para 44-53.

pressure to undergo an interview without an appropriate adult being present; and being pressured into signing a statement which they were unable to read.<sup>332</sup> These examples are all likely breaches of the Police and Criminal Evidence Act (“PACE”) 1984 and the PACE Codes of Practice.

211. The PRT also told us about the concerns of people with learning disabilities with their experiences at court, including being unaware of what was happening during trial and an inability to understand decisions of the court, including on bail and sentencing.<sup>333</sup>

**212. We are concerned that the problems highlighted by this evidence could have potentially very serious implications for the rights of people with learning disabilities to a fair hearing, as protected by the common law and by Article 6 ECHR. Some of this evidence also suggests that there are serious failings in the criminal justice system, which give rise to the discriminatory treatment of people with learning disabilities.**

## Prisoners

213. The PRT told us about a significant number of prisoners, who, because of their disability, are excluded from aspects of the prison regime, including offender behaviour programmes. In particular:

- lack of support for this group of prisoners;
- unreliability of screening and assessment tools in identifying learning disabilities and learning difficulties;
- gaps in the provision of services and support to prisoners with learning disabilities and a lack of clarity on how to access services.

214. The PRT told us about a significant number of prisoners who, because of their disability, are excluded from offender behaviour programmes. This delays their parole dates and affects their resettlement opportunities, leading to people with learning disabilities spending longer in prison than prisoners who are in a comparable situation, but who do not have learning disabilities.<sup>334</sup> Mencap and the Foundation for People with Learning Disabilities agreed with this assessment.<sup>335</sup>

**215. The evidence which we have received on the treatment of people with learning disabilities in prison and their inability to secure equal access to parole, raises one of the most serious issues in our inquiry. We are deeply concerned that this evidence indicates that, because of a failure to provide for their needs, people with learning disabilities may serve longer custodial sentences than others convicted of comparable crimes. This clearly engages Article 5 ECHR (right to liberty) and Article 14 (enjoyment of ECHR rights without discrimination). It is also an area that falls within the Prison Service’s responsibilities under the Disability Equality Duty.**

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<sup>332</sup> Ev 167, 3.1.

<sup>333</sup> Ev 169, 4.1.

<sup>334</sup> Ev 173, Annex 3, para 52.

<sup>335</sup> Ev 144, 215. See also Ev 82, 334.

216. In its recently published consultation document *Improving Health, Supporting Justice*, the Government has recognised that further work is required to assist in identifying people with learning disabilities in prison and addressing their needs.<sup>336</sup>

217. **We welcome the publication of the Government’s consultation, *Improving Health, Supporting Justice*. We recommend that the Government ensures that people with learning disabilities are able to participate effectively in that consultation. We recommend that each of the relevant criminal justice agencies, including the police, the Crown Prosecution Service, the Court Service, the Prison Service and the Probation Service undertake an audit of their services for compliance with ECHR rights, the Disability Discrimination Act and, specifically, the Disability Equality Duty, in order to inform the Government’s *Improving Health, Supporting Justice*, when it is finalised next year.**

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<sup>336</sup> Department of Health, *Improving Health, Supporting Justice: A Consultation Document, A strategy for improving health and social care services for people in the criminal justice system*, 27th November 2007, pp 20-1.

## 8 Barriers to an 'ordinary life'

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218. A significant number of witnesses told us that the main reason why their human rights are at risk is because there are significant barriers to their participation in the wider community. They explained that adults with learning disabilities have fewer opportunities to make the choices and decisions that those without learning disabilities would consider part of 'ordinary life'. These barriers included funding and inability to access support, negative attitudes and stereotypes (considered in Chapter 4) and fear of crime (considered in Chapter 7).

219. We now consider four additional barriers which we consider capable of undermining adults with learning disabilities' rights: lack of accessible information; lack of access to independent advocacy; access to voting rights; and lack of support for participation in the local community. We explain below how, by addressing some of these barriers, people with learning disabilities could be empowered to speak up for their own human rights and to enhance protection of those rights.

### Access to information

I think we don't get enough help when filling in council forms because I don't understand the forms. This makes me feel very frustrated because I am a non reader with learning difficulties. I feel that social services do not make things easy for me. My social worker bosses me around and does not include me in decision making, this may be because I don't like saying anything because he makes me feel stupid ... This makes me feel that I am not treated fairly as an adult.

*A learner from Linkage Community Trust<sup>337</sup>*

Information is power, and currently, most information rests with service commissioners and providers. If people are to have real choice in their lives, then much more independent information needs to be available.

*British Institute of Learning Disabilities<sup>338</sup>*

220. A recurring theme in the evidence was the lack of easy to understand, illustrated information to enable people with learning disabilities (most of whom have some difficulties with reading) to have more choice and control over their everyday lives. If people with learning disabilities are really to enjoy life like other people, as Government policy intends, then they also need easy to understand information on all the issues related

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<sup>337</sup> Annex 2, para 8.

<sup>338</sup> Ev 348.

to day-to-day living “such as health, housing, benefits, employment, crime and safety”<sup>339</sup> as well as “access to a football stadium or civil rights such as getting married”.<sup>340</sup>

221. *Valuing People Now* states that:

Providing accessible information is essential if people are to have more choice and control over their lives and is an implicit expectation of the Disability Discrimination Act.<sup>341</sup>

222. The Cambridgeshire Parliament of people with learning disabilities told us:

We need to know the same information as everyone else, but we need to have it broken down and with pictures.<sup>342</sup>

223. Cheshire and Wirral Partnership NHS Trust said:

Without accessible information we are reducing peoples ability to be empowered, take control of their lives and advocate for themselves...we make people over reliant on carers or others.<sup>343</sup>

224. The Disability Rights Commission told us:

Not enough groups make their information easy to read and understand. Groups like the Government and local councils should always do this.<sup>344</sup>

**225. Under the Disability Discrimination Act 1995 (as amended), the statutory obligation on providers of goods and services to the public to make reasonable adjustments to enable disabled people to use their services may, in some circumstances, require that information is made available to people with learning disabilities in an easy to understand, written, or other appropriate format. We consider that the provision of accessible information for people with learning disabilities should be standard practice for public bodies such as the Government departments, NHS bodies and local authorities, who are all subject to this duty to make reasonable adjustments, and are also subject to the duty to promote disability equality.**

**226. With the introduction of the Disability Discrimination Act (as amended) and the duty on providers of goods and services to make reasonable adjustments to meet the needs of people with learning disabilities, we believe that adults with learning disabilities should be able to obtain the information they need in formats they can understand. We consider that the statutory obligation to make reasonable adjustments includes ensuring that information is available in an easy to understand format. This duty is reinforced in relation to public authorities, by the Disability Equality Duty. We are deeply concerned that this does not reflect the experiences of our witnesses.**

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<sup>339</sup> Ev 391.

<sup>340</sup> Ev 335.

<sup>341</sup> *Valuing People Now*, para 9.2.7.

<sup>342</sup> Ev 69.

<sup>343</sup> Ev 78.

<sup>344</sup> Ev 199.

227. A member of Macclesfield Speaking Up Speaking Out Group told us:

I recently had an operation...I need a special diet. I couldn't read the menu [in hospital] because I can't read and write, and kept telling the staff, but I only got the right food on the last day<sup>345</sup>

228. Members of CHANGE said:

Benefits information is not accessible. There is no information or letters that have pictures and easy words<sup>346</sup>

229. The absence of accessible information (from statutory authorities and private voluntary or commercial organisations) may have potentially disastrous consequences: for example, someone taking too high a dose of the medication prescribed to them.<sup>347</sup> But on an everyday basis, it makes 'an ordinary life' hard to achieve. It makes it difficult for people with learning disabilities to open a bank account.<sup>348</sup> It makes it hard for people to make decisions for themselves.<sup>349</sup> It increases people's dependency on others to explain things and violates their privacy, as their personal information is shared.<sup>350</sup> It makes it difficult for adults with learning disabilities to make complaints.<sup>351</sup> The provision of accessible information can help in all these cases, and also help people protect themselves, for example against crime and abuse.<sup>352</sup>

230. We welcome the statement in *Valuing People Now*<sup>353</sup> that:

Government will work to improve its performance in this area [of providing accessible information] and expects all other public, voluntary and private bodies to do the same – in particular by employing self-advocacy organizations to advise and develop materials.

**231. We are disappointed by the lack of specificity in this statement and at the absence of any reference to goals, targets or identifiable commitments to increase the provision of accessible information in the Action Summary relating to this section of *Valuing People Now*. It is not clear how progress is to be made or measured in the absence of any specific commitments. We recommend that such commitments are included in the revised version of *Valuing People Now* to be produced later in 2008, following consultation.**

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<sup>345</sup> Submission of the Macclesfield Speaking Up, Speaking Out Group. Available from the Parliamentary Archives.

<sup>346</sup> Ev 151.

<sup>347</sup> Ibid.

<sup>348</sup> Ev 223.

<sup>349</sup> Ev 119.

<sup>350</sup> Ev 264.

<sup>351</sup> Ev 200.

<sup>352</sup> Ev 263.

<sup>353</sup> *Valuing People Now*, para 9.2.7.

232. Given the considerable evidence we have received on the importance of accessible information for people with learning disabilities **we recommend that it receive appropriate attention in the ODI's forthcoming Independent Living Review Strategy.**

233. **In addition, we call on the ODI to ensure that statutory authorities and others are fulfilling their duties under the Disability Discrimination Act and the Disability Equality Duty by making information available in formats that are accessible to people with learning disabilities. This can be through providing it themselves, by commissioning it from others, or requiring it as part of contractual agreements. The ODI should monitor and review progress as part of an overall strategy for the provision of accessible information.**

234. **We also call upon the Healthcare Commission and the Commission for Social Care Inspection to ensure that scrutiny of the availability of accessible information (including easy to understand information on what is abusive practice and what people can do about it) is routinely included in the course of their inspections of providers of health and social care.**

### ***Accessible information on human rights***

235. In Chapter 3, we talked about the importance of increasing understanding of human rights principles and legal standards by adults with learning disabilities. From the evidence we received, it seemed information about human rights, specifically aimed at people with learning disabilities, was scarce. For example, Values Into Action said:

I think it is fair to say that in the 50 groups that we visited there was very little awareness of the Human Rights Act among people with learning difficulties themselves and professionals.<sup>354</sup>

236. A positive exception was the work undertaken by Values Into Action providing information and training on legal and human rights to learning disabilities self-advocacy groups in different parts of the country.<sup>355</sup>

237. We received evidence that people with learning disabilities are keenly interested in human rights and information about rights and responsibilities.<sup>356</sup> But we were disappointed to learn how difficult it is for them to find reliable and accessible information on their legal rights and responsibilities, the implications of legislation such as the Human Rights Act for them, and what they can do to defend or pursue their rights.

238. **Empowering people with learning disabilities to stand up for their human rights is important. Although, in some places in this report, we have described this group as vulnerable, we have been particularly impressed by the role played by self-advocacy groups and our individual witnesses with learning disabilities, in telling us how their rights could best be protected. We are aware that some people with learning disabilities will not be able to understand information about human rights by themselves, even if it**

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<sup>354</sup> Q 49.

<sup>355</sup> VIA, *Rights for All Project*, <http://viauk.org/rights.htm>.

<sup>356</sup> See for example. Annex 2, para 10.

**is in an easy read, illustrated or audio format. They will need to have the information explained and have support to understand it.**<sup>357</sup>

239. Where vulnerable people are involved, particularly in relation to public authorities or service providers, principal responsibility for securing respect for the rights of service users must be with the provider. In our view, there is a clear need for staff to receive more information on human rights.

240. Cheshire and Wirral NHS Partnership Trust learning disabilities division told us:

Despite there being a national drive for accessible information there is no central steer or indeed commitment to ensuring information within health care settings is available in forms accessible to people with learning disabilities.<sup>358</sup>

241. **These concerns are indicative of a disappointing lack of central leadership on this issue. We were deeply disappointed that the Office for Disability Issues could not provide an accessible summary of the United Nations Convention on the Rights of Persons with Disabilities until more than a year after the Convention was agreed. We were equally concerned that the Easy Read guide to the Human Rights Act, prepared by the Ministry of Justice, was not available to be downloaded from the Ministry of Justice website for some time. We raised these concerns with the Minister for Human Rights and the Minister for Disabled People and both of these problems have now been resolved.**<sup>359</sup>

242. **We welcome the recent publications from the Office for Disability Issues on improving information for disabled people, including the document aimed at public sector communicators and practitioners. These set out five principles for producing better information for disabled people:**

**Principle 1: ensure that disabled people are involved from the start.**

**Principle 2: provide information through a range of channels and formats.**

**Principle 3: ensure your information meets users' needs.**

**Principle 4: clearly signpost other services.**

**Principle 5: always define responsibility for information provision.**<sup>360</sup>

**These principles should be followed both within and beyond Government.**

243. We asked the Minister for Disabled People whether there was any cross-Government strategy on the provision of easy read information on rights. She told us that she would “probably be less than honest if she said that there was a strategy.” She explained:

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<sup>357</sup> Ev 69.

<sup>358</sup> Ev 78.

<sup>359</sup> Ev 404, 405.

<sup>360</sup> Office for Disability Issues, *Five principles for producing better information for disabled people*, February 2007.

There is increasing awareness of the importance of alternative formats and that is something that the Office for Disability Issues is working on. Certainly, we have encouraged other departments, where they are publishing information and documents, to look at alternative formats.<sup>361</sup>

**244. We were dismayed by the Minister's frank admission that not only is there no Government strategy on the provision of accessible information on rights, there is no wider cross-Government strategy on providing information in an accessible format. We accept that it can sometimes be difficult to provide information in this way quickly, consultation with relevant stakeholders will often be appropriate and necessary, and that, sometimes, the most appropriate format will not be the written word. Nevertheless, we expect central Government to provide a lead and to set a good example by ensuring that people with learning disabilities have equal access to information in appropriate formats, as required by the Disability Discrimination Act and the Disability Equality Duty.**

**245. We recommend that the Office for Disability Issues work with the Office of the National Director for Learning Disabilities at the Department of Health and the Cabinet Office to formulate and implement a cross-Government strategy for the provision and distribution of easy to understand, accessible information, by Government (and other) bodies, as a matter of urgency. We recommend that a specific strategy on accessible information about human rights and equality is formulated by the Office of Disability Issues, working with the Ministry of Justice. The Equality and Human Rights Commission should be closely involved in the development of these strategies and should monitor their implementation in practice.**

## Access to independent advocacy

What would help people with learning disabilities get their human rights? More self advocacy workers to help people speak up for themselves. More representational advocates to take up specific cases and act on people's behalf. More investment in getting the right sort of information out there in a form that people understand.<sup>362</sup>

246. Access to easy to understand information is one step in securing people's human rights, but for many people with learning disabilities it will not be enough; they will need advocacy, help and support to defend or claim their rights.<sup>363</sup> As Speaking Up For Yourself in Brent told us:

information in itself will not automatically mean that disabled people with learning difficulties will have the strength to stand up for their rights. Many of us have grown

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<sup>361</sup> Q 213.

<sup>362</sup> Annex 2, para 8.

<sup>363</sup> Ev 147.

up accepting limitations being imposed upon us by parents, schools and service providers and therefore not see them as possible human rights violations.<sup>364</sup>

247. Many witnesses were clear that accessible information and independent advocacy needed to go hand in hand. People needed support during assessments and reviews, in taking decisions, making complaints and in many other ways, if they were to secure their rights.<sup>365</sup> Advocates were instrumental in challenging inappropriate restraint (e.g. people being strapped to a chair or wheelchair; or being forced to wear splints, to prevent putting hands in mouth); intervening for better health care; addressing lack of privacy or risk of abuse from others; securing the benefits to which people were entitled; supporting personal relationships; helping parents receive the support they need to get their children returned to them<sup>366</sup> or supporting young people in the transition from school to adult life; helping adults with housing problems; helping individuals involved in the protection of vulnerable adults process; and helping people make video statements at the local police station and with court appearances.<sup>367</sup>

248. Independent advocacy is particularly important for people with profound and multiple disabilities, who do not use speech to communicate. They are not well represented by self advocacy groups, on Partnership Boards, or on other national, regional and local fora of people with learning disabilities. The result is that their needs remain low on the Government agenda.<sup>368</sup> While their need is arguably the greatest (they are unlikely to communicate via speech or sign language, yet they are largely surrounded by a workforce that is not trained to understand their communication method) they are, paradoxically, poorly served by advocacy services.<sup>369</sup>

People with profound and multiple learning disabilities have the greatest need for advocacy, but they have limited access to it. One survey showed that only 11% of advocacy schemes could support a person with profound and multiple learning disabilities.<sup>370</sup>

249. *Valuing People* was clear about the potentially powerful impact of advocacy:

Effective advocacy can transform the lives of people with learning disabilities by enabling them to express their wishes and aspirations and make real choices.<sup>371</sup>

Substantial funding was made available in its wake to support both self and citizen advocacy over a number of years.

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<sup>364</sup> Ev 381-82.

<sup>365</sup> Ev 200-01.

<sup>366</sup> Ev 337-43 (Advocacy Partners).

<sup>367</sup> Ev 125.

<sup>368</sup> Ev 205.

<sup>369</sup> *Ibid.*

<sup>370</sup> *Ibid.*

<sup>371</sup> Department of Health, *Valuing People: A New Strategy for Learning Disability for the 21<sup>st</sup> Century*, Cm 5086, March 2001, para.4.5.

250. *Valuing People Now* also endorses the importance of advocacy. It refers to three different types of advocacy: self-advocacy (where people with learning disabilities come together to speak up for themselves); citizen advocacy (where volunteers speak up on behalf of someone); and professional or representational advocacy (where people are paid to advocate on someone's behalf on a short or long term basis).<sup>372</sup> It is not clear, however, how far any national commitment to supporting advocacy goes, the extent to which it embraces independent advocacy (as opposed to self advocacy) or the extent of any funding for advocacy.

251. *Improving the Life Chances of Disabled People* made a commitment to ensuring there was one user-led organization, modelled on existing Centres for Independent Living, in each locality (defined as a council with social services responsibilities) by 2010, a commitment reiterated in *Valuing People Now*.<sup>373</sup> Such a commitment, while welcome, does not remove the need for independent advocacy for people with a learning disability.

252. The British Institute of Learning Disabilities, amongst others, told us:

Access to independent advocacy ... is dependent on a post code lottery as there is no guarantee of the availability of advocacy for all those who need it. Funding for advocacy schemes tends to be very fragile and short term in nature.<sup>374</sup>

Moreover, organisations are often very small and spend a great deal of their limited capacity applying for short term funding.<sup>375</sup> Many of those submitting evidence to us argued for proper resourcing of advocacy services “to meet the growing demand in referrals and to challenge discriminatory practice”.<sup>376</sup>

253. The Mental Capacity Act 2005 introduced a specific form of independent advocacy service. NHS bodies and local authorities (‘the responsible bodies’) must ensure that independent mental capacity advocates (IMCAs) are available to support people who lack capacity to make important decisions in relation to serious medical treatment or a long term change in accommodation. The responsible bodies can extend the IMCA service to decisions relating to care plans and adult protection cases, but this is not mandatory.<sup>377</sup>

254. However, the IMCA service is only available to those individuals who do not have any family or friends who could be consulted about those decisions (referred to as being ‘unbefriended’; which means that the person has no friends or relatives who it would be appropriate to consult in determining what would be in the person's best interests). During the passage of the Mental Capacity Bill, it was argued that anyone who lacked capacity, not just those who did not have family or friends who could be consulted, should be entitled to an advocate, but this was opposed by the Government on resource grounds.<sup>378</sup> A number

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<sup>372</sup> Department of Health, *Valuing People Now: From Progress to Transformation*, December 2007, para 9.2.2.

<sup>373</sup> *Ibid*, para 9.2.6.

<sup>374</sup> Ev 348.

<sup>375</sup> Ev 219.

<sup>376</sup> Ev 122.

<sup>377</sup> Ev 147. See also the Mental Capacity Act 2005, Code of Practice 10.41.

<sup>378</sup> Ev 147.

of those submitting evidence to us argued strongly that the IMCA service should not be restricted to those who are ‘unbefriended’, if people with learning disabilities were to be supported in asserting their human rights.<sup>379</sup> For example, Scope said:

We believe that widespread access to non-instructed independent advocacy is vital to protecting the rights of people who lack mental capacity in a much wider variety of situations.<sup>380</sup>

255. We share these concerns. Our understanding is that many people accessing IMCA services will have significant barriers to communication and will be unable to instruct the advocate themselves (this is referred to as ‘non-instructed advocacy’). In addition it is likely that many people using the IMCA service will be unable to express a view about the proposed decision.<sup>381</sup> However, we believe that many people who have family and friends will be in a similar situation and will also require the help of a specialist independent advocate to safeguard their interests. **We call upon the Government to review the availability of Independent Mental Capacity Advocate services.**

256. Parents with learning disabilities, in particular, have been shown to benefit greatly from independent advocacy.<sup>382</sup> This mitigates the difficulties they often have in their dealings with social workers, health visitors or school staff, who may lack experience of learning disability and be unaware of how best to communicate with them or to provide them with support. But many parents do not have access to advocacy, despite the recognition in *Valuing People Now* that: “Research evidence illustrates a need for independent advocacy” to support them.<sup>383</sup> As Rotherham Advocacy Partnerships pointed out:

This leaves people in a situation where they are not given the opportunity to participate in assessments and processes in a way that is meaningful to them. It denies them the opportunity to do justice to their skills and abilities. It can also leave them confused and bewildered about what is happening around them.<sup>384</sup>

It may also result in their children being placed away from their family home.<sup>385</sup>

257. The Government’s *Good Practice Guidance on Working with Parents with a Learning Disability* states that:

Independent advocacy should always be provided where children are the subject of a child protection plan and/or care proceedings instituted.

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<sup>379</sup> Ev 201.

<sup>380</sup> Ev 83.

<sup>381</sup> ‘Making decisions: The Independent Mental Capacity (IMCA) service’, [www.dca.gov.uk/legal-policy/mental-capacity/mibooklets/booklet06.pdf](http://www.dca.gov.uk/legal-policy/mental-capacity/mibooklets/booklet06.pdf).

<sup>382</sup> We consider the rights of parents more generally, in Chapter 6.

<sup>383</sup> Department of Health, *Valuing People Now: From Progress to Transformation*, Dec 2007, para 12.4.1.3.

<sup>384</sup> Ev 357.

<sup>385</sup> Ev 315.

Any parent involved in a child protection conference and/or care proceedings should be informed about local and national sources of independent advocacy. It is particularly important that parents with learning disabilities have access to independent advocacy in these situations. Commissioning strategies should address the availability of local advocacy...as these are not always readily available.<sup>386</sup>

**258. We recommend that parents with learning disabilities should have access to independent advocacy when subject to safeguarding procedures, particularly before any court proceedings. We call upon the Government to review current provision of advocacy services for parents with learning disabilities, to ensure that such services are available in these situations.**

259. We received a good deal of evidence about the difficulties confronted by people with learning disabilities in trying to make complaints about potential breaches of their human rights.<sup>387</sup> We welcome the Government's proposals for reforming complaints procedures across health and social care by making them simpler, more accessible and user friendly, with independent specialist advocacy available where necessary.<sup>388</sup> When the new procedures come into effect, it will be important for the Government, under the Disability Equality Duty, to monitor the extent to which people with learning disabilities are making use of these new procedures and their access to independent advocacy in doing so; and to ensure that their use of complaints procedures and advocacy support is proportionate.

**260. We are aware that resources are limited, but are persuaded that for many people with learning disabilities access to independent advocacy may be the only realistic means of securing their human rights, not least if family carers are no longer around to advocate on their behalf.** In many cases, moreover, we are convinced that, as Learning Disability Alliance Scotland said:

Proper support at critical times in people's lives can prevent the need for more serious (and expensive) interventions at a later stage.<sup>389</sup>

**261. We consider that adults with learning disabilities, particularly those who are most vulnerable (including parents, adults with complex and profound learning disabilities and those involved in the criminal justice system), would benefit greatly from the assistance of independent advocates in order to secure their human rights on the same basis as the rest of society.**

262. Rob Greig, National Co-Director for Learning Disability told us, however, that:

Whilst funding of advocacy is important, it is also important that we help improve the quality of advocacy organisations. I do not just mean self-advocacy, I mean citizen advocacy and professional advocacy as well...there is the same onus on

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<sup>386</sup> DfES/DH, *Good Practice Guidance on Working with Parents with a Learning Disability*, June 2007 [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_075119](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_075119).

<sup>387</sup> See for example: Ev 200-01.

<sup>388</sup> Department of Health, *Making Experience Count: a new approach to responding to complaints* [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_078565](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_078565).

<sup>389</sup> Ev 336.

advocacy organisations to demonstrate impact and effectiveness as there is in any other organisations.<sup>390</sup>

263. Under *Valuing People Now*, the *Valuing People* national advocacy fund will change to focus on supporting advocacy to have greater impact, rather than pump priming new groups, as before. This will include self-advocacy leadership development. The fund will “pay particular attention to people at greatest risk of losing choice and control in their lives, such as those from ethnic minority communities and people with complex support needs.” **We welcome this commitment, but call upon the Government to review the availability of independent advocacy for people with learning disabilities whose needs fall outside the scope of the Independent Mental Capacity Advocate services provided under the Mental Capacity Act 2005, or the proposed reform of health and social care complaints procedures. We recommend that as part of their proposal to support advocacy to have an increasing impact, the Government ensures that independent advocates, including independent mental capacity advocates and others, have an understanding of human rights principles and the positive duties of public authorities and service providers towards adults with learning disabilities.**

## Voting rights

264. People with learning disabilities have the same right to vote as everyone else. As Members of Parliament, we were particularly concerned to hear about the significant barriers most people with learning disabilities face in exercising this right.

265. Voting is not covered by the Mental Capacity Act 2005. The test for capacity to vote (which has a relatively low threshold) therefore remains unchanged.<sup>391</sup> Potential voters need only show ‘a capacity to understand in “broad terms” the nature and effect of voting and an ability to make a choice between candidates’.<sup>392</sup> However, witnesses told us that the assumption that people with learning disabilities lack the capacity to vote is a common problem. Scope commented:

In 2001 in Oxfordshire a group of Scope service users were turned away from their polling station because the Presiding Officer decided that they were not capable of voting. Such arbitrary judgments are a common occurrence for people with complex impairments.<sup>393</sup>

266. We received evidence that suggests people with learning disabilities may have difficulties in registering to vote. A study of the electoral register for Cambridgeshire carried out by the Centre for Participation found that only 66% of people receiving learning disability services were registered to vote, compared to 95% for the rest of the local population.<sup>394</sup> Scope informed us that they had anecdotal evidence of people with learning

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<sup>390</sup> Q 151.

<sup>391</sup> Section 29 of the Mental Capacity Act 2005 excludes decisions on voting from the remit of the Act.

<sup>392</sup> *Assessment of Mental Capacity, Guidance for Doctors and Lawyers*, 2<sup>nd</sup> edition, British Medical Association and The Law Society, 2004, 90.

<sup>393</sup> Ev 86.

<sup>394</sup> Ev 117.

difficulties in residential settings not being told when their voter registration form arrives because staff thought that the service users were not capable of voting.<sup>395</sup>

267. Being included on the electoral register is only the first step in the electoral process. The Centre for Participation's study found that only 22% of those people with learning disabilities registered to vote actually did so, compared to 61% for the population as a whole. Eve Rank, Disability Rights Commissioner, told us:

The problem is that some residential homes for people with learning difficulties actually take the voting cards away because they believe their residents do not understand the voting systems.<sup>396</sup>

268. Ms Rank suggested that care homes should be monitored by the Commission for Social Care Inspection as part of their inspections, to find out how many residents with learning disabilities voted in the general election.

269. Ms Rank told us that people with learning disabilities could be supported to exercise their right to vote independently. She told us that the Disability Rights Commission Learning Disability Action Group had prepared a pack for prospective voters and had organised some successful training events. She suggested that the Electoral Commission could have a role in relation to this support.<sup>397</sup>

270. The Centre for Participation told us that too little is being done to enable people with learning disabilities to engage in the political process.<sup>398</sup> A similar comment was made by members of Colchester Local Action Group who felt that they had been ignored by the political parties in the recent elections and it had been hard to translate the flyers so that people with learning disabilities could understand them.<sup>399</sup> Scope's survey of people with learning disabilities found that 49% of the respondents thought the polling station would be inaccessible to a voter with learning disabilities and 50% of the respondents said that staff at polling stations were unhelpful.<sup>400</sup>

271. Article 29 of the UN Disability Rights Convention requires states to take measures to uphold the right and opportunity for disabled people to vote by, by for example:

Ensuring that voting procedures, facilities and materials are appropriate, accessible and easy to understand and use.

272. We are pleased to note that Scope is working with the Electoral Commission and the Ministry of Justice on matters such as clarifying how capacity to vote is assessed.<sup>401</sup> **People with learning disabilities should be subject to the same test for capacity to vote as people without learning disabilities. However, assumptions that adults with learning**

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<sup>395</sup> Ev 86.

<sup>396</sup> Q 35.

<sup>397</sup> Q 35.

<sup>398</sup> Ev 117.

<sup>399</sup> Ev 129.

<sup>400</sup> Ev 86.

<sup>401</sup> Ev 86.

disabilities lack capacity may prevent them from exercising their right to vote and to participate in the democratic process.

273. We recommend that the Electoral Commission and the Ministry of Justice, working with the Office of the National Director for Learning Disabilities and the Equality and Human Rights Commission, produce guidance for Presiding Officers on the test for capacity to vote and how to assess this. The Electoral Commission should work together with the Equality and Human Rights Commission to take steps to make voting more accessible for people with learning disabilities. As part of this process, we recommend that the Government consider the role of the proposed Care Quality Commission, and whether it should monitor how registered providers of care facilitate, or undermine, service users' rights to vote.

### Support to participate in the local community

274. Article 8 ECHR has been interpreted by the European Court of Human Rights as including a right to participate in the life of one's local community.<sup>402</sup> Under the UN Disability Rights Convention State parties are obliged to "take effective measures" to facilitate the full inclusion and participation of disabled people in the community. People with learning disabilities often need support to participate in ordinary community life, but such support is often lacking.<sup>403</sup>

275. A key concern voiced by many of those giving evidence were the barriers they faced in trying to participate in the social life of their local community. These ranged from unwelcoming, hostile, or unhelpful attitudes from people in cafes<sup>404</sup> or other local facilities,<sup>405</sup> lack of accessible information,<sup>406</sup> difficulties in accessing transport to get to places,<sup>407</sup> venues that were physically inaccessible,<sup>408</sup> the increasing closure of public toilets<sup>409</sup> and of other local facilities like post offices and shops,<sup>410</sup> and fears for their personal safety (because of experiences of harassment), all of which made people more likely to stay at home.<sup>411</sup>

276. The most common barrier to participating in the social life of the community was the lack of support to enable people to go out, to visit friends, or pursue individual interests.

Most of us are expected to stay at home during the weekend because there is not enough staff to help us go out and do the things that [are] of interest to us, including visiting friends and family. It is hard to do something else on the spur of the moment

<sup>402</sup> *Botta v Italy* [1998] 26 EHRR 241.

<sup>403</sup> Ev 232.

<sup>404</sup> Ev 328.

<sup>405</sup> Ev 223.

<sup>406</sup> *Ibid.*

<sup>407</sup> Ev 328.

<sup>408</sup> Ev 223.

<sup>409</sup> Ev 217-18.

<sup>410</sup> *Ibid.*

<sup>411</sup> Ev 328, 218.

or indeed with notice because there is not enough staff to support us to follow our own interests and lives. We see this as having our liberty deprived by services.<sup>412</sup>

277. Unless people had access to an advocate,<sup>413</sup> or good one-to-one, or self-directed, support<sup>414</sup> (for example, via individual budgets) which enabled them to pursue their own social activities and relationships, people generally had to go out, if they went out at all, as a group.<sup>415</sup> As Pembrokeshire Advocacy noted:

Predominantly the residents have either to go out as a group or not at all. This...reinforces the institutionalized medical model of care.<sup>416</sup>

278. Staff rotas operate as a further constraint on people having the opportunity of a normal social life. Wokingham Learning Disability Partnership Board told us:

People with a learning disability don't have the same opportunities to extend their networks and form relationships as other members of the community...lots of people with learning disabilities lives are governed by services and staff rotas – rather than being able to lead a life that they want and meet the people that they want.<sup>417</sup>

279. Colchester Mencap said:

Carers' shifts often change at 9pm. This means that [adults with learning disabilities] are forced to leave a leisure venue at 8.30pm to be back at their home for the changeover.<sup>418</sup>

280. We welcome the acknowledgement in *Valuing People Now* of the importance to people of friendships and relationships and its statement that although:

promoting personal relationships is not something that central government has a direct role [in],...it is something that local commissioners and service providers should pay general attention to.<sup>419</sup>

281. We also welcome its recommendation that local commissioners and service providers should therefore pay greater attention to:

organising service provision in a way that helps people's social contacts e.g. not designing shift patterns that curtail people's social lives.<sup>420</sup>

282. We are not confident, however, that this change will be brought about unless there is a more robust requirement on commissioners and service providers to change their

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<sup>412</sup> Ev 381.

<sup>413</sup> Ev 342.

<sup>414</sup> Ev 330.

<sup>415</sup> Ev 328.

<sup>416</sup> Ev 121.

<sup>417</sup> Ev 357.

<sup>418</sup> Ev 129.

<sup>419</sup> Department of Health, *Valuing People Now: From Progress to Transformation*, Dec 2007, para 12.3.2.

<sup>420</sup> Ibid.

practices, and to take a more human rights based approach to service provision. **We recommend that when *Valuing People Now* is revised, after consultation, local commissioners and service providers should pay greater attention to how they organise services, in order to maximize, rather than limit, people’s opportunities for social relationships and inclusion in the community.**<sup>421</sup>

283. It was clear from the evidence that we received that participation in the local community is even more difficult for some groups than for others, for example, those living with older carers,<sup>422</sup> those in rural areas<sup>423</sup> and those with profound and multiple disabilities.<sup>424</sup> Of particular concern were the circumstances of people who were not provided with the aids they needed in order to communicate with other people. Find A Voice, a voluntary organisation helping people without speech, told us:

With our help, Keith obtained £9000 worth of funding and is now able to use his [communication] aid at meetings, on the train and to order a Chinese take-away. He can access services and is actively participating in the life of the community.<sup>425</sup>

**284. We recommend that the final version of *Valuing People Now* consider the devastating impact which poor access to communication aids can have on the ability of some adults with learning disabilities to communicate with others, and thus participate in social relationships and the life of the community.**

285. Some people, particularly those described as having “challenging behaviour” or complex support needs, are placed many miles away from their families and communities in out of area placements.<sup>426</sup> In 2006, 31% of people with learning disabilities aged 18-64 known to councils (over 11,000 people) were in residential accommodation outside their home area.<sup>427</sup> Yet there is general recognition that this is not usually good practice.<sup>428</sup> The government’s own strategy as set out in *Our Health, Our Care, Our Say* is “to ... focus on those with complex needs and to shift care closer to home”.<sup>429</sup> Placing people miles away from their families and local communities goes against this policy, and as the Centre for Participation in Cambridge pointed out, has a number of negative effects:

First, it restricts the opportunity for continuing family contact particularly as many are from families who are socially and financially disadvantaged.

Secondly, there may be little monitoring by the funding authorities given the distance thus the possibility of undetected abuse, exploitation, or neglect.

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<sup>421</sup> Ibid.

<sup>422</sup> Ev 317.

<sup>423</sup> Ev 298.

<sup>424</sup> Ev 345.

<sup>425</sup> Ev 49.

<sup>426</sup> Ev 232, for example.

<sup>427</sup> Ev 213.

<sup>428</sup> Ev 181, para 2.9.

<sup>429</sup> Department of Health, *Our Health, Our Care, Our Say*, Cm 6737, 2006, para 31.

286. In addition, funding places in far away services takes significant investment from local services.<sup>430</sup> There is a very limited likelihood of people's social inclusion in the communities in which they end up, at the very time that they are likely to experience less contact with their family and friends in their community of origin.

287. As the Challenging Behaviour Foundation said:

It is obvious that if a parent lives 300 miles from their adult son/daughter they are going to be able to visit them less than if they live 3 miles away.<sup>431</sup>

**288. We recommend that the Department of Health gathers and publishes information on the nature and numbers of out of county placements, and on the significant impact such placements have on individuals with learning disabilities, to inform its work on the revised version of *Valuing People Now*.**

### **Role of service providers**

289. We asked the National Co-Director for Learning Disabilities about who had responsibility for ensuring that the individual rights of adults with learning disabilities are respected. He told the Committee that the responsibility was shared three ways: firstly with individual supporters or providers (e.g. support workers); secondly with managers and service provider organisations and, where the service was commissioned from a provider, with the commissioning public authority; finally, he thought it should be the responsibility of regulators to detect breaches.<sup>432</sup> We have considered these duties elsewhere in this Report.

290. In previous reports we have expressed our serious concern that due to the restrictive interpretation of our national courts on the meaning of 'public authority' a range of bodies, including private care homes and voluntary organisations fall outside the remit of the HRA.<sup>433</sup> We consider that this leaves many vulnerable people without the protection afforded by the HRA. The concerns that we highlighted about older people in healthcare are also relevant to people with learning disabilities. A large number of adults with learning disabilities will be receiving care in the private sector. The Commission for Social Care Inspection state that as at 31 March 2006 there were 57,587 places in care homes registered with the Commission for younger adults with learning disabilities. They also estimate that 9 out of 10 care homes for adults aged 18 – 64 (many of whom are people with learning disabilities) are in the private and voluntary sector.<sup>434</sup>

**291. In light of the significant role commissioners and service providers will play in the protection and promotion of the human rights of adults with learning disabilities, we were disappointed that the recently published Department of Health *Good Practice***

<sup>430</sup> Ev 345.

<sup>431</sup> Ev 245.

<sup>432</sup> Q 138.

<sup>433</sup> See for example, Eighteenth Report of Session 2006-07, *The Human Rights of Older People in Healthcare*, HL Paper 156-I, HC 378-I, paras 154–61.

<sup>434</sup> Ev 318.

*Guidance for Commissioning Specialist Adult Learning Disability Health Services*<sup>435</sup> fails entirely to mention “human rights” or a “human rights based approach”, or to provide any practical guidance to commissioners on how to use commissioning agreements to secure respect for the rights of adults with learning disabilities.

292. The Minister told us the Government intended to ensure that the new Care Quality Commission would be under a responsibility to regulate to the “standards that would be expected if the Human Rights Act were to apply to those providers”.<sup>436</sup> The Human Rights Minister recently told us that a statutory solution which will extend the full protection of the Human Rights Act to service users who receive support from a private sector provider will not happen until after the conclusion of a consultation on its forthcoming Green Paper on a Bill of Rights for Britain.<sup>437</sup> We consider that this presents a significant retreat from the Government’s earlier commitment to provide a solution for private care homes as soon as possible.<sup>438</sup> We are concerned that this change of view will leave a significant gap in the protection of vulnerable people receiving support in the private sector, including adults with learning disabilities. We recommend that the Government legislate to ensure that all private providers of health and social care are considered public authorities for the purpose of the Human Rights Act and are subject to the duty to comply with Convention rights.<sup>439</sup>

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<sup>435</sup> Commissioning specialist adult learning disability health services - Good practice guidance, Department of Health, 31 October 2007.

<sup>436</sup> First Report of Session 2007-08 ‘Government Response to the Committee’s Eighteenth Report of Session 2006-07: the Human Rights of Older People in Healthcare’ HL Paper 5; HC 72.

<sup>437</sup> Eighth Report of Session 2007-08, *Legislative Scrutiny: Health and Social Care Bill*, HL Paper 46, HC 303, para 1.1.

<sup>438</sup> HC Debate, 15 June 2007, Cols 1045-1047.

<sup>439</sup> For a full explanation of the Committee’s views on the application of the Human Rights Act 1998 to the provision of health and social care, see Eighth Report of Session 2007-08, *Legislative Scrutiny: Health and Social Care Bill*, HL Paper 46, HC 303, para 1.6-1.18.

## 9 Conclusions: Putting human rights principles into practice

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The test of Government policy has to be the experiences of citizens we are trying to support.

*Mr Ivan Lewis, MP, Minister for Care Services<sup>440</sup>*

293. In the course of our recent inquiries on the treatment of asylum seekers and the human rights of older people in healthcare, we have raised our concerns about the lack of respect afforded to the human rights of the some of the most marginalised and vulnerable members of our society. In the course of this inquiry, these concerns have intensified. The evidence reveals that adults with learning disabilities continue to face a high level of prejudice and discrimination, ranging from patronising behaviour to criminal assaults. This is unacceptable.

294. In this report, we have made a number of recommendations to the Government, to health and social care inspectorates, to the Equality and Human Rights Commission and others. Our recommendations are based on our view that there is an urgent need for stronger leadership to create a more positive culture of respect for human rights in the United Kingdom.

295. Although we accept that there is a lot of work to be done with the general population to promote a rights based culture, we have been deeply disappointed in the course of this inquiry by the low level of awareness of human rights principles and of the Human Rights Act 1998 among not only adults with learning disabilities, their carers and supporters, but also among those who work in the field and at the heart of local and central Government. **Although we were impressed by the passion for a human rights based approach expressed by the Minister for Care Services and the Minister for Disabled People, we are persuaded that real change for adults with learning disabilities will only happen if practical steps are taken to promote a more positive approach to the rights of adults with learning disabilities on the ground, in mainstream public services.**

296. However, this practical approach, using the Human Rights Act 1998, and the Disability Discrimination Act (as amended), to improve and encourage best practice in service delivery should not undermine the binding nature of these important statutory obligations. **Public authorities should never be allowed to treat their duties towards adults with learning disabilities under the Human Rights Act 1998 and the Disability Discrimination Act (including their positive duties under the Disability Equality Duty) as optional.**

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<sup>440</sup> Q 154.

## The role of Government

297. We welcome the commitment of Government to increased choice and participation for adults with learning disabilities in *Valuing People* and *Valuing People Now* (and by the regional and devolved administrations in each of the equivalent policy papers in Scotland, Wales and Northern Ireland). We are, however, disappointed by the lack of strong leadership shown by central Government in the implementation of these policies in a way which ensures the fundamental rights of adults with learning disabilities are respected. We welcome the very positive work of the Office of the National Director and his colleagues in the *Valuing People* Support Team; but we are anxious about the clear evidence that this work, and the aims of Government policy, are being undermined by a failure to pay serious attention to both *Valuing People* and the wider rights of adults with learning disabilities in other Government departments and in mainstream public service delivery.

298. The National Co-Director for Learning Disabilities described the process of engaging other Government departments in the implementation of *Valuing People*, as a “process of dialogue and negotiation” with other departments, to persuade them that making provision for adults with learning disabilities in their mainstream policies was a priority.<sup>441</sup> On the one hand, the Minister for Care Services told us that the creation of the Office of Disability Issues and the Life Chances Ministerial Group meant that the disability agenda was “uniquely” being “driven across Government”.<sup>442</sup> Yet, on the other, he told us that even within his own Department, he had found it a “struggle” to get the mainstream NHS to take the needs of adults with learning disabilities seriously.<sup>443</sup> The Government should provide consistent leadership on the need to respect the human rights of adults with learning disabilities. *Valuing People Now* recognises the increased work by other Departments in meeting the needs of adults with learning disabilities (for example, work by the Home Office on criminal justice issues), which we welcome, but we are concerned that there has been only limited evidence of constructive joint-working by Government on these issues so far.

299. We recognise that in most instances, principal responsibility for meeting the needs of adults with learning disabilities will be with service providers, either in local authorities, or PCTs. With this in mind, we were particularly concerned by the evidence that, for many, change has been slow and progress undermined by limited resources at a local level, despite the Government’s lofty and admirable aims to promote independent living and the rights of adults with learning disabilities. For example, when we asked the National Co-Director for Learning Disabilities about consistent implementation of *Valuing People*, he told us:

There is a great difference between authorities ... there are even great differences within authorities, because if we remember that the *Valuing People* agenda is a cross-Government agenda, what you can often find, even amongst the better authorities, is some really innovative progress in one area, maybe about access to mainstream healthcare, but maybe not doing much around access to paid work.<sup>444</sup>

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<sup>441</sup> Q 133.

<sup>442</sup> Q 157.

<sup>443</sup> Q 158.

<sup>444</sup> Q 123.

300. We asked the Minister for Care Services and the Minister for Disabled People about the introduction of new Public Service Agreement on Equalities and Social Exclusion, and the balance between local and central responsibility for implementation of policies on learning disabilities. We welcome the Minister's recognition that "to achieve real change you need to empower far more the professionals on the frontline" and his commitment not to "stop challenging the system when I believe it is fundamentally failing in its basic obligations to ... people with learning disabilities".<sup>445</sup>

**301. We urge the Department of Health and the Office for Disability Issues to consider opportunities for joint-working to meet the aims of *Valuing People* and *Valuing People Now*. As part of this process, we recommend the amendment of *Valuing People Now*, to remind all public authorities, including Government Departments, local authorities and NHS Trusts, that the aim of the Government's policy is grounded both in the need to respect the human rights of adults with learning disabilities, and in the binding obligations of the Human Rights Act 1998 and the Disability Discrimination Act (as amended). We consider that this would send a strong message to mainstream services that implementation of this policy is not optional.**

### The role of the Equality and Human Rights Commission

302. In the course of this inquiry, we have considered a number of positive steps taken by the former Disability Rights Commission to highlight inequalities faced by adults with learning disabilities, not least in the work of the DRC Formal Inquiry Panel on health inequalities. We were impressed by the evidence of Eve Rank, the Disability Rights Commissioner and Chair of the DRC Learning Disability Action Group.

303. The Equality and Human Rights Commission, which assumed the responsibilities of the DRC in October 2007, is newly established and is in the process of setting longer term goals and priorities. We intend to take oral evidence from the Commission during 2008 on its early work and emerging priorities. However, **we consider that the Equality and Human Rights Commission has a crucial role to play in the creation of a broad culture of human rights.** It has an important general duty to work "to ensure mutual respect between groups based on ... shared respect for equality and human rights"<sup>446</sup> and a specific duty to "promote awareness, understanding and protection of human rights".<sup>447</sup> In the course of this inquiry, we have learnt that the best way to improve respect for the human rights of adults with learning disabilities, is to involve them in the work done to help, support and empower them. **We encourage the Equality and Human Rights Commission to ensure that it monitors the performance of the Government and other public bodies in relation to the treatment of adults with learning disabilities, and take steps, including through active involvement with their statutory Disability Committee or otherwise, to ensure that adults with learning disabilities play a central role in its work and that their views and voices are heard.**

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<sup>445</sup> Q 171.

<sup>446</sup> Equality Act 2006, Section 3.

<sup>447</sup> Equality Act 2006, Section 9.

## Conclusions and recommendations

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### Adults with learning disabilities: the key issues

1. We received evidence from across the UK, but most was from organisations and individuals in England. Consequently, this Report will focus largely on the policy framework in *Valuing People*. However, the human rights standards discussed in this Report are universal. We consider that most of the conclusions that can be drawn from the evidence are equally relevant to all four countries of the UK. Equally, we hope that our recommendations and conclusions will inform the development of policy and practice by each of the devolved administrations, as well as central Government. (Paragraph 31)
2. In the light of the evidence which we received on the gap between the aims of *Valuing People* and the experience of adults with learning disabilities, which we consider below in Chapter 4, we are concerned that in *Valuing People Now* there appear to be few measurable targets for action nor precise proposals for monitoring progress on their achievement. (Paragraph 38)
3. We are pleased to note that the Government is committed to “fully consider and respond to the conclusions” of our Report in the course of formulating their priorities for 2008 - 2011. We expect the Government to give the recommendations and conclusions of our Report serious consideration during preparation of the final version of *Valuing People Now* and in setting its priorities for action for the next three years. We consider that *Valuing People Now* presents a valuable opportunity for the Department of Health to take a positive approach towards the promotion of the understanding and protection of the human rights of adults with learning disabilities. We recommend that, when redrafted after consultation, *Valuing People Now* should explicitly promote a “human rights based approach” to public authorities’ duties under the Human Rights Act; and should provide practical guidance for public authorities on the effective implementation of those duties. (Paragraph 40)

### Why do human rights matter?

4. We are disappointed that, at the start of the 21st century, almost ten years after the introduction of the Human Rights Act, and over a year since the introduction of the Disability Equality Duty, [the] evidence received convinces us that we need to emphasise that adults with learning disabilities have the same human rights as everyone else; and that they are entitled to freedom, respect, equality, dignity and autonomy in their everyday lives. (Paragraph 44)
5. We recently made a number of recommendations to Government on “the transformative power of the Human Rights Act”. In plain English, we told the Government and others what we thought they needed to do to make the Human Rights Act work for everyone. We have called upon the Government, the Equality and Human Rights Commission, other public bodies and voluntary organisations to champion publicly how a better understanding of human rights principles could

improve health and social care services. (Paragraph 53) We consider that when fulfilling this duty, the Equality and Human Rights Commission has a responsibility to engage proactively with those who are most vulnerable to breaches of their human rights and those who are less likely to be able to understand what human rights mean for them, including adults with learning disabilities. We recommend that the Commission take steps to ensure that adults with learning disabilities are aware of their rights under the Human Rights Act and the Disability Discrimination Act (as amended). (Paragraph 53)

6. We recommend that the Minister for Care Services, the Office for Disability Issues and the Ministry of Justice together develop a strategy on how to help vulnerable people, including adults with learning disabilities, understand what the statutory duties in the Human Rights Act and the Disability Equality Duty mean for them. (Paragraph 54)
7. We consider that the statutory duties under the Disability Discrimination Act (as amended), and specifically, the Disability Equality Duty, complement the HRA. Together they form a powerful means of effecting positive change. If both are understood and implemented properly they can underpin and promote the agenda set by the Government for improving the life chances of people with learning disabilities. (Paragraph 56)
8. We are concerned that, one year after the introduction of the Disability Equality Duty, the evidence we have received suggests a clear distinction between formal compliance by public authorities and a failure to take a positive approach to the duty on the ground. (Paragraph 60) We recommend that the Office for Disability Issues work closely with the Equality and Human Rights Commission to champion publicly a broad, positive approach to the Disability Equality Duty. This should involve a strategy to ensure that other public bodies, and their staff, understand how the proactive implementation of the duty can improve service provision for adults with learning disabilities and others. (Paragraph 60)
9. We urge the Government to ensure that any amendment to existing positive equality duties should strengthen rather than undermine their effectiveness. (Paragraph 61)
10. We agree that the UN Disability Rights Convention presents a valuable opportunity to confirm that disabled people, including adults with learning disabilities, are entitled to full respect for their human rights. (Paragraph 66)
11. We welcome the Government's commitment to ratify the UN Disability Rights Convention. However, we are mystified by the reason given for the Government's delay in ratifying this treaty. (Paragraph 69)
12. We recommend that either the Government ratifies the UN Disability Rights Convention and its Optional Protocol without further delay, or provides clear and unambiguous details of any specific impediments to immediate ratification. We will continue to monitor progress towards ratification. We will be deeply concerned if the Government does not meet the goal that the Minister for Disabled People has set, namely, ratification before the end of 2008. (Paragraph 70)

13. We welcome the commitment expressed by the Minister for Care Services and the Minister for Disabled People, to the principle of independent living. We await the results of the Government's Independent Living Review, with interest. We recommend that the Government consider the outcomes of that review, and the need for any further policy or legislative change, as part of their commitment to review the UK's domestic compliance with the UN Disability Rights Convention. (Paragraph 77)

### Living with a learning disability

14. We recommend that the Department of Health revisit this issue [of how can support adults with learning disabilities to form relationships] in their redrafted *Valuing People Now*, in light of the evidence we have received. (Paragraph 88)
15. We are concerned that the experiences communicated to us by adults with learning disabilities, their families and supporters appear to reflect the findings of the last National Survey, that adults with learning disabilities are more likely than other people to suffer from social exclusion, poverty and isolation. (Paragraph 98)
16. We are concerned by the evidence that the framework for improving the lives of adults with learning disabilities does not appear to have had much impact in Government departments other than the Department of Health or the wider public sector; and that the impact of *Valuing People* on the experiences of adults with learning disabilities in their dealings with local authorities and individual service providers has been so patchy. (Paragraph 104)
17. We were dismayed to hear the Minister for Care Services describe the National Director for Learning Disabilities as a "lone-ranger" on mainstreaming learning disabilities, rights and policy even within the Department of Health. We are extremely concerned that the Department, which has responsibility for cross-Government policy on learning disability, has failed to take seriously access to mainstream services for adults with learning disabilities, despite the existence of its statutory duties under the Disability Discrimination Act (as amended), the Disability Equality Duty and the Human Rights Act. (Paragraph 105)
18. We welcome the Government's recognition that further work needs to be done to implement policy effectively, so as to support the rights of adults with learning disabilities as individuals. We also welcome the Minister's frank acknowledgement that more pressure needs to be placed on both central and local Government to deliver the policy of *Valuing People*. (Paragraph 108)
19. We are concerned that the National Co-Director for Learning Disabilities and the Government have been searching for "levers" to implement a policy designed to ensure that adults with learning disabilities can live their lives in a way which promotes dignity and respect for their rights. We are particularly concerned that the National Co-Director did not appear to consider that public authorities' duties under the Human Rights Act would hold much sway. We reiterate our concern that the Department of Health and other Government departments should be proactive in promoting a positive approach to the Human Rights Act and to the Disability

Equality Duty. We see the value of using these obligations to support or explain a particular policy choice as a ‘lever’ for implementation. However, this should not undermine the binding nature of these duties. (Paragraph 109)

20. Difficult questions about allocation of resources may be involved when deciding whether to provide [funding for] support in specific cases. However, we consider these questions must be answered within the context of the legal obligations of local authorities and other public authorities, to respect the dignity and rights of service users. Local authorities must act in accordance with the Disability Equality Duty. (Paragraph 116)
21. We are deeply concerned about the Government’s negative response to our recommendations on the need for an express positive human rights duty for public authorities. The creation of a positive duty to respect human rights would help kick-start a change of attitude to the role of the Human Rights Act and to rights more generally. We doubt that, at least in the short term, oversight by the Equality and Human Rights Commission will encourage individual authorities to take a more proactive approach. On the other hand, witnesses to this inquiry, including the Minister for Care Services and the Minister for Disabled People, stressed their view that the potential impact of the Disability Equality Duty will be to change fundamentally the way that public authorities look at disability rights. We remain persuaded that the same is true of positive duties and the Human Rights Act. We reiterate our recommendation that the Government consider the introduction of an express positive duty on public authorities to promote respect for human rights, where the European Convention on Human Rights imposes a positive obligation on the State. (Paragraph 117)
22. We strongly recommend that guidance to local councils should remind them that decisions about funding must be taken in a way which is compatible with the Disability Equality Duty and the Human Rights Act. We recommend that the Government rewrite its Guidance, including *Fair Access to Care*, to ensure it provides clear, straightforward and accessible examples of a human rights based approach, explains how social care funding decisions could lead to a breach of Convention rights and sets out how to comply proactively with the Disability Equality Duty. (Paragraph 121)
23. We agree with our witnesses that one of the most distressing and worrying things about the investigation by the Healthcare Commission and CSCI into the treatment of people with learning disabilities in Cornwall was that “many of the staff did not believe and understand that what they were doing was wrong”. This episode provides a most harrowing example of how a lack of awareness of the rights of people with learning disabilities can have a devastating effect, leading to situations where the right to be treated with respect for private life is ignored (Article 8 ECHR), and the rights to life and to be free from inhuman and degrading treatment are endangered (Articles 2 and 3 ECHR). (Paragraph 127)
24. We agree that taking a human rights based approach to service provision could contribute to reversing negative attitudes, assumptions and stereotypes. We again stress that the Department of Health and the Office for Disability Issues should take a

lead in creating a positive approach to the implementation of both the Human Rights Act 1998 and the Disability Equality Duty. However, “taking a human rights based approach” means more than using the appropriate language in policy documents or in statements to parliamentary committees. A proactive and practical approach to the implementation of individual rights for people with learning disabilities is needed to replace the existing culture, which has allowed society to “dehumanise” people with learning disabilities for centuries (Paragraph 133)

### **The treatment of adults with learning disabilities in health and residential care settings**

25. We are concerned, but not surprised, that the evidence we received shows that people with learning disabilities face similar problems in healthcare as older people, including: (Paragraph 136)
- Malnutrition and dehydration (Articles 2, 3 and 8 ECHR):
  - Abusive and degrading treatment (Articles 2, 3 and 8 ECHR):
  - Neglect or carelessness by health and social care services (Articles 2, 3 and 8 ECHR):
  - Lack of privacy in health and social care settings (Article 8 ECHR):
  - Lack of dignity in respect of personal care needs (Article 8 ECHR):
  - Inappropriate use of restraint and/or medication (Article 8 ECHR):
  - Problems with communication, particularly where patients have complex or profound learning disabilities (Article 8 ECHR):
  - Negative, patronising and infantilising attitudes towards people with learning disabilities (Article 8 ECHR):
  - Discriminatory treatment of adults with learning disabilities in access to mainstream services on grounds related to their disability (Articles 2, 3, 8 and 14 ECHR):
  - Fear and difficulties in making complaints (Article 8 ECHR):
26. We are extremely concerned that adults with learning disabilities undergo degrading experiences in health and residential care settings, which closely mirror the experiences of older people, on which we reported in August 2007. This implies that poor treatment and neglect of some of the most vulnerable people in our society, at the times when they are ill, in need of care and support, and most dependent on others to secure their most basic and fundamental rights, is endemic. Treatment involving abuse, neglect or carelessness of the kind uncovered by the Healthcare Commission and the Commission for Social Care Inspection in Cornwall and Sutton and Merton and by Mencap in *Death by Indifference* involves serious and severe human rights breaches. The task of securing the dignity and self-respect of this vulnerable group, which is central to the fulfilment of their human rights, is the

responsibility of us all. The creation of a more positive human rights culture in service provision is vital to securing respect for adults with learning disability in need of health and social care services. (Paragraph 139)

27. We made a series of recommendations on how to meet these concerns, in our Report on the *Human Rights of Older People in Healthcare*. In the light of the evidence that human rights problems extend beyond older people to a broad range of vulnerable people, we are extremely concerned that the Department of Health has offered few concrete commitments in its response to our previous recommendations on the implementation of a human rights based approach in the NHS (Paragraph 142)
28. While we agree that the HRA is an important 'lever for change', care must be taken when using such descriptions to ensure that the legal obligations of the Human Rights Act are not undermined or misunderstood. (Paragraph 146)
29. We welcome confirmation by the Department of Health that an independent evaluator has been appointed for its Human Rights in Healthcare project. It is disappointing that the report of the independent evaluator will not be available until Autumn 2008, which will be almost eight years after the HRA was introduced. Nonetheless, we recommend that the findings of the evaluation are published and disseminated widely within the Department of Health (including to Strategic Health Authorities, PCTs and providers of health and social services) and across Government. (Paragraph 147)
30. Despite our view that the Human Rights in Healthcare project has potential, we are concerned that the Department of Health may see this exercise as a panacea that will lead to a positive culture of respect for dignity and human rights in service provision. In our view, this is only one of a range of initiatives that is needed in order to achieve this aim. We recommend that the Department of Health should use the sixtieth anniversary of the NHS to gain maximum exposure for its positive commitment to ensure that "Human rights are at the centre of the values of the health and social care system in this country". We consider that the adoption of a clear strategy on human rights in policy making by the Department of Health would set a positive example on the type of culture change which will be necessary to ensure that human rights are really at the heart of service delivery. (Paragraph 148)
31. We welcome the positive commitment by the Healthcare Commission and CSCI to a human rights based approach to regulation and inspection. We also welcome the commitment of the Healthcare Commission and CSCI to work together to implement the conclusions of the recent Healthcare Commission Audit. We recommend that the Healthcare Commission and CSCI use this process to promote a positive approach to human rights and to the National Minimum Standards by hospitals and care homes. (Paragraph 150)
32. The Health and Social Care Bill proposes to merge the regulatory and inspection systems for health and social care. The Care Quality Commission will assume the responsibilities currently held by the Healthcare Commission and CSCI in 2009. The Government proposes to merge the National Minimum Standards for health and social care, in registration requirements for registered providers of health and social

care. It proposes that “human rights will be an important feature in the requirements, and we expect that they will also feature prominently in the regulator’s criteria”. We will consider these proposals as part of our scrutiny of the Health and Social Care Bill. (Paragraph 151)

33. We welcome the early Government commitment in *Valuing People Now* to use the forthcoming NHS Operating Framework to require Strategic Health Authorities, PCTs and Trusts to deliver action plans to address the shortcomings identified by the Healthcare Commission’s audit of learning disability services. (Paragraph 152)
34. We welcome the frank acknowledgement by the Minister for Care Services that more needs to be done to ensure that adults with learning disabilities can access health services on an equal basis. We consider that practical steps must be taken to meet the recommendations of the DRC Formal Inquiry, not only by the Department of Health, but by other public bodies, including Strategic Health Authorities, PCTs, and local authorities. We are disappointed that progress on implementing the recommendations by the DRC Formal Inquiry has been slow. We welcome the commitment in *Valuing People Now* that work will continue until “nationally led responses to the DRC recommendations are in place”. We urge the Department of Health to provide visible national leadership on the recommendations of the DRC Formal Inquiry, by taking steps to assess progress on each recommendation and to provide a detailed strategy and timetable for implementation. We support the recommendation of the DRC Formal Inquiry, that this should take place with much greater urgency. We recommend that the Equality and Human Rights Commission continue the work of the DRC on this issue and monitor progress closely over the next year, with a view to taking enforcement action if no progress is made. (Paragraph 156)
35. We welcome the Department of Health announcement of the independent inquiry into the healthcare of people with learning disabilities. We also welcome the Government’s commitment in *Valuing People Now* to consider seriously the recommendations of that inquiry on hospital and acute care. We welcome the Government’s decision to highlight the duties of PCTs and general hospital trusts under the Disability Discrimination Act 1995 (as amended). This includes ensuring that their Disability Equality Schemes address those bodies ability and resources to meet the needs of people with learning disabilities. We regret that such a reminder is necessary. (Paragraph 157)
36. In the light of the evidence gathered in this report, we call on the independent inquiry to adopt a human rights based approach to its work. We trust that it will endorse our call for a positive approach to the implementation of the statutory duties in the Human Rights Act and the Disability Discrimination Act 1995 (as amended). We will follow the progress of this inquiry with interest. (Paragraph 158)

### Parenting and family life

37. Social Services departments, courts and other public authorities working with parents with learning disabilities and their children are subject to the duty to act compatibly with the right to respect for family life, as guaranteed by Article 8 ECHR.

The State has a positive, human rights based obligation to protect children from harm and to promote their development. However, any decision which impinges on the relationship between a parent with learning disabilities and his or her children could have very serious implications for the right to respect for their family life. In such circumstances, particular care must be taken to ensure that any restrictions on the development of ordinary family relationships must not only be in the best interests of the child, but must also be a necessary and proportionate response to the level of risk posed to the child or to its parents through continuing care at home. This assessment must take into account all of the relevant facts of an individual case, including the potential for additional support to meet the needs of the parents and the child. (Paragraph 163)

38. The Minister for Care Services told us that “political correctness” should not prevent the removal of a child simply because a parent has learning disabilities. We agree that the assessment of whether a child should or should not remain with its parents is a complex one, requiring the careful consideration of many factors, including the best interests of the child and the rights of the child and its parents. We welcome the Minister’s acknowledgement that unless justified and proportionate in all the circumstances, removal of a child could pose a significant risk to the rights of the child and its parents to respect for family life (Paragraph 164)
39. We welcome the acknowledgement in the Government’s *Good Practice Guidance on Working with Parents with a Learning Disability* that people with learning disabilities “have the right to be supported in their parenting role, just as their children have the right to live in a safe and supportive environment.” We also welcome the acknowledgement that while children have the right to be safe from harm, children’s needs are usually best met by support for their parents, to look after them. (Paragraph 169)
40. We consider that if the recommendations for good practice in each of these areas were implemented effectively, this could significantly reduce the risk that parents and children would be separated, in breach of [their human rights]. (Paragraph 170)
41. We welcome the recognition in *Valuing People Now* of the need to do more to improve support to parents with learning disabilities and their children. But we remain concerned that there are few concrete proposals for action or measurable targets regarding improving support to parents with learning disabilities and their children in that document. (Paragraph 177)
42. Although we welcome the commitment of the Department of Health and the Department for Children, Schools and Families to the provision of information [to parents] in an accessible way, the Minister for Disabled People has accepted that it is likely that this commitment is no more than the Disability Discrimination Act already requires of those Departments. (Paragraph 178)
43. While we recognise the potential of the *Good Practice Guidance* to improve support for parents with learning disabilities and their children, its effectiveness will depend entirely on positive dissemination and widespread implementation by local authority adults’ and children’s services, NHS Trusts and others. We are disappointed that the

active dissemination of this important Guidance has so far relied principally upon the work of an independent parenting network, albeit supported by the Office of the National Director and his colleagues. We welcome the proposed involvement of the Care Services Improvement Partnership in further dissemination of the Guidance. We call upon the Government to set out clearly its proposals for ensuring that all local authority social services departments, including children's services and NHS Trusts are aware of the *Good Practice Guidance* and, importantly, that relevant professionals have training in its effective implementation. (Paragraph 179)

44. We note that although *Valuing People Now* refers to the need for independent advocacy for parents with learning disabilities, it makes no proposals for action to ensure and increase the availability of such provision. We call upon the Government to take action on this issue in our discussion of advocacy in Chapter 8 below. (Paragraph 180)
45. We consider that the proposals for monitoring progress in [this part of] *Valuing People Now* are particularly weak and lack precision. Public authorities have binding duties under the Disability Discrimination Act and the Human Rights Act to provide services without discrimination, to implement effectively their positive duties to disabled people, and to uphold the rights of parents with learning disabilities and their children to respect for their private life. In the light of these duties, we recommend that the Department of Health requires Learning Disability Partnership Boards to report annually on local commissioning of services to support parents with learning disabilities; and ensures that data is collected locally on the numbers of parents with learning disabilities supported by community teams for people with learning disabilities, and the numbers of their children taken into care, each year. (Paragraph 181)

### Treatment of people with learning disabilities in the criminal justice system

46. We recognise that not all abuse against adults with learning disability will amount to criminal behaviour. We recognise that in many circumstances, individuals who uncover abuse and criminal behaviour against vulnerable adults will rightly treat the protection of the victim as a priority. Where an individual has been seriously assaulted or where his or her life has been endangered, there is a clear obligation on the State, secured by that individual's ECHR rights, to conduct an effective investigation of the circumstances of the abuse. This includes an obligation to provide for the prosecution of the individual responsible, if appropriate. These important human rights obligations apply to everyone, including people with learning disabilities, unless there are objective reasons why an investigation or a prosecution should not go ahead. (Paragraph 195)
47. We recommend that in the review of *No Secrets* and the proposed *Valuing People Now* guidance on crime and people with learning disabilities, the Government provides clear and accessible guidance on protecting people with learning disabilities (and other vulnerable adults) from abuse and ensuring that if a crime is suspected, effective steps are taken to inform and involve the police. We urge the Government to ensure that the relevant criminal justice agencies, including the Association of Chief Police Officers, the Crown Prosecution Service, the Home Office and

organisations of and for people with learning disabilities, are closely involved in shaping this guidance. (Paragraph 196)

48. We are disappointed that the Government has not agreed to create a duty to report abuse, as we previously recommended. We call on the Department of Health, as part of their review of the *No Secrets* Guidance, to reconsider our recommendation that there should be a duty on those working with vulnerable adults, at least within the NHS and in care homes to report suspected abuse. (Paragraph 197)
49. People with learning disabilities, in common with the wider population, may have mixed experiences of dealing with the police, the courts and other parts of the criminal justice system. Every part of that system has an obligation to promote equal access to their services for disabled people, including those with learning disabilities, as part of their duties under the Disability Equality Duty. (Paragraph 200)
50. We welcome the Government's commitment to meet the concerns of people with learning disabilities about hate crime, in *Valuing People Now*. We welcome the proposal that the Home Office should lead on the production of guidance to address hate crime and to increase the safety of people with learning disabilities in their communities. We recommend that people with learning disabilities, their carers and supporters, ACPO, the Police Federation and the CPS are closely involved in the production of this guidance. We consider that more accurate information would better inform the Government's policy on this issue. As part of the Government's commitment to address hate crime and the personal safety of adults with learning disabilities, we recommend that steps be taken to gather more consistent data on the level of crime against people with learning disabilities, either through a survey sponsored by the Home Office, or as part of the British Crime Survey. (Paragraph 204)
51. We welcome the recent steps taken by ACPO and the CPS to improve their policy on crimes against victims with disabilities and hate crime, including against adults with learning disabilities. We were disappointed to hear that the CPS had not initially worked closely with the National Co-Director for Learning Disabilities. We recommend that, where any public sector agency is considering a policy which is relevant to disabled people, steps are taken to ensure that people with learning disabilities are specifically considered as part of the policy formulation, and if possible, involved in the preparation of that policy. We welcome the proposal by the CPS to amend their charging guidance to ensure that they are involved at an early stage in the investigation of crimes against people with a learning disability where hate crime is suspected. Whilst any decision on prosecution must be based upon the evidence available and should take full account of the rights of the defendant, we consider that this would be a positive development which could increase the confidence of adults with learning disability in the police and the criminal justice system, by ensuring that any element of hostility or prejudice towards them is properly investigated and considered as part of any prosecution. (Paragraph 209)
52. We are concerned that the problems highlighted by this evidence could have potentially very serious implications for the rights of people with learning disabilities to a fair hearing, as protected by the common law and by Article 6 ECHR. Some of

this evidence also suggests that there are serious failings in the criminal justice system, which give rise to the discriminatory treatment of people with learning disabilities. (Paragraph 212)

53. The evidence which we have received on the treatment of people with learning disabilities in prison and their inability to secure equal access to parole, raises one of the most serious issues in our inquiry. We are deeply concerned that this evidence indicates that, because of a failure to provide for their needs, people with learning disabilities may serve longer custodial sentences than others convicted of comparable crimes. This clearly engages Article 5 ECHR (right to liberty) and Article 14 (enjoyment of ECHR rights without discrimination). It is also an area that falls within the Prison Services' responsibilities under the Disability Equality Duty. (Paragraph 215)
54. We welcome the publication of the Government's consultation, *Improving Health, Supporting Justice*. We recommend that the Government ensures that people with learning disabilities are able to participate effectively in that consultation. We recommend that each of the relevant criminal justice agencies, including the police, the Crown Prosecution Service, the Court Service, the Prison Service and the Probation Service undertake an audit of their services for compliance with ECHR rights, the Disability Discrimination Act and, specifically, the Disability Equality Duty, in order to inform the Government's *Improving Health, Supporting Justice*, when it is finalised next year. (Paragraph 217)

### Barriers to an 'ordinary life'

55. Under the Disability Discrimination Act 1995 (as amended), the statutory obligation on providers of goods and services to the public to make reasonable adjustments to enable disabled people to use their services may, in some circumstances, require that information is made available to people with learning disabilities in an easy to understand, written, or other appropriate format. We consider that the provision of accessible information for people with learning disabilities should be standard practice for public bodies such as the Government departments, NHS bodies and local authorities, who are all subject to this duty to make reasonable adjustments, and are also subject to the duty to promote disability equality. (Paragraph 225)
56. With the introduction of the Disability Discrimination Act (as amended) and the duty on providers of goods and services to make reasonable adjustments to meet the needs of people with learning disabilities, we believe that adults with learning disabilities should be able to obtain the information they need in formats they can understand. We consider that the statutory obligation to make reasonable adjustments includes ensuring that information is available in an easy to understand format. This duty is reinforced in relation to public authorities, by the Disability Equality Duty. We are deeply concerned that this does not reflect the experiences of our witnesses. (Paragraph 226)
57. We are disappointed by the lack of specificity and at the absence of any reference to goals, targets or identifiable commitments to increase the provision of accessible information in the Action Summary relating to this section of *Valuing People Now*

[on accessible information]. It is not clear how progress is to be made or measured in the absence of any specific commitments. We recommend that such commitments are included in the revised version of Valuing People Now to be produced later in 2008, following consultation. (Paragraph 231)

58. We recommend that [the issue of accessible information] receive appropriate attention in the ODI's forthcoming Independent Living Review Strategy. (Paragraph 232)
59. In addition, we call on the ODI to ensure that statutory authorities and others are fulfilling their duties under the Disability Discrimination Act and the Disability Equality Duty by making information available in formats that are accessible to people with learning disabilities. This can be through providing it themselves, by commissioning it from others, or requiring it as part of contractual agreements. The ODI should monitor and review progress as part of an overall strategy for the provision of accessible information. (Paragraph 233)
60. We also call upon the Healthcare Commission and the Commission for Social Care Inspection to ensure that scrutiny of the availability of accessible information (including easy to understand information on what is abusive practice and what people can do about it) is routinely included in the course of their inspections of providers of health and social care. (Paragraph 234)
61. Empowering people with learning disabilities to stand up for their human rights is important. Although, in some places in this report, we have described this group as vulnerable, we have been particularly impressed by the role played by self-advocacy groups and our individual witnesses with learning disabilities, in telling us how their rights could best be protected. We are aware that some people with learning disabilities will not be able to understand information about human rights by themselves, even if it is in an easy read, illustrated or audio format. They will need to have the information explained and have support to understand it (Paragraph 238)
62. These concerns are indicative of a disappointing lack of central leadership on this issue. We were deeply disappointed that the Office for Disability Issues could not provide an accessible summary of the United Nations Convention on the Rights of Persons with Disabilities until more than a year after the Convention was agreed. We were equally concerned that the Easy Read guide to the Human Rights Act, prepared by the Ministry of Justice, was not available to be downloaded from the Ministry of Justice website for some time. We raised these concerns with the Minister for Human Rights and the Minister for Disabled People and both of these problems have now been resolved. (Paragraph 241)
63. We welcome the recent publications from the Office for Disability Issues on improving information for disabled people, including the document aimed at public sector communicators and practitioners. These set out five principles for producing better information for disabled people: (Paragraph 242)
  - Principle 1: ensure that disabled people are involved from the start.
  - Principle 2: provide information through a range of channels and formats.

- Principle 3: ensure your information meets users' needs.
- Principle 4: clearly signpost other services.
- Principle 5: always define responsibility for information provision.

These principles should be followed both within and beyond Government.

64. We were dismayed by the Minister's frank admission that not only is there no Government strategy on the provision of accessible information on rights, there is no wider cross-Government strategy on providing information in an accessible format. We accept that it can sometimes be difficult to provide information in this way quickly, consultation with relevant stakeholders will often be appropriate and necessary, and that, sometimes, the most appropriate format will not be the written word. Nevertheless, we expect central Government to provide a lead and to set a good example by ensuring that people with learning disabilities have equal access to information in appropriate formats, as required by the Disability Discrimination Act and the Disability Equality Duty. (Paragraph 244)
65. We recommend that the Office for Disability Issues work with the Office of the National Director for Learning Disabilities at the Department of Health and the Cabinet Office to formulate and implement a cross-Government strategy for the provision and distribution of easy to understand, accessible information, by Government (and other) bodies, as a matter of urgency. We recommend that a specific strategy on accessible information about human rights and equality is formulated by the Office of Disability Issues, working with the Ministry of Justice. The Equality and Human Rights Commission should be closely involved in the development of these strategies and should monitor their implementation in practice. (Paragraph 245)
66. We call upon the Government to review the availability of Independent Mental Capacity Advocate services. (Paragraph 255)
67. We recommend that parents with learning disabilities should have access to independent advocacy when subject to safeguarding procedures, particularly before any court proceedings. We call upon the Government to review current provision of advocacy services for parents with learning disabilities, to ensure that such services are available in these situations. (Paragraph 258)
68. We are aware that resources are limited, but are persuaded that for many people with learning disabilities access to independent advocacy may be the only realistic means of securing their human rights, not least if family carers are no longer around to advocate on their behalf (Paragraph 260)
69. We consider that adults with learning disabilities, particularly those who are most vulnerable (including parents, adults with complex and profound learning disabilities and those involved in the criminal justice system), would benefit greatly from the assistance of independent advocates in order to secure their human rights on the same basis as the rest of society. (Paragraph 261)

70. We welcome this commitment [*Valuing People Now*: on the national advocacy fund], but call upon the Government to review the availability of independent advocacy for people with learning disabilities whose needs fall outside the scope of the Independent Mental Capacity Advocate services provided under the Mental Capacity Act 2005, or the proposed reform of health and social care complaints procedures. We recommend that as part of their proposal to support advocacy to have an increasing impact, the Government ensures that independent advocates, including independent mental capacity advocates and others, have an understanding of human rights principles and the positive duties of public authorities and service providers towards adults with learning disabilities. (Paragraph 263)
71. People with learning disabilities should be subject to the same test for capacity to vote as people without learning disabilities. However, assumptions that adults with learning disabilities lack capacity may prevent them from exercising their right to vote and to participate in the democratic process. (Paragraph 272)
72. We recommend that the Electoral Commission and the Ministry of Justice, working with the Office of the National Director for Learning Disabilities and the Equality and Human Rights Commission, produce guidance for Presiding Officers on the test for capacity to vote and how to assess this. The Electoral Commission should work together with the Equality and Human Rights Commission to take steps to make voting more accessible for people with learning disabilities. As part of this process, we recommend that the Government consider the role of the proposed Care Quality Commission, and whether it should monitor how registered providers of care facilitate, or undermine, service users rights to vote. (Paragraph 273)
73. We recommend that when *Valuing People Now* is revised, after consultation, local commissioners and service providers should pay greater attention to how they organise services, in order to maximize, rather than limit, people's opportunities for social relationships and inclusion in the community (Paragraph 282)
74. We recommend that the final version of *Valuing People Now* consider the devastating impact which poor access to communication aids can have on the ability of some adults with learning disabilities to communicate with others, and thus participate in social relationships and the life of the community. (Paragraph 284)
75. We recommend that the Department of Health gathers and publishes information on the nature and numbers of out of county placements, and on the significant impact such placements have on individuals with learning disabilities, to inform its work on the revised version of *Valuing People Now*. (Paragraph 288)
76. In light of the significant role commissioners and service providers will play in the protection and promotion of the human rights of adults with learning disabilities, we were disappointed that the recently published Department of Health Good Practice Guidance for Commissioning Specialist Adult Learning Disability Health Services fails entirely to mention "human rights" or a "human rights based approach" or to provide any practical guidance to commissioners on how to use commissioning agreements to secure respect for the rights of adults with learning disabilities. (Paragraph 291)

77. The Minister told us the Government intended to ensure that the new Care Quality Commission would be under a responsibility to regulate to the “standards that would be expected if the Human Rights Act were to apply to those providers”. The Human Rights Minister recently told us that a statutory solution which will extend the full protection of the Human Rights Act to service users who receive support from a private sector provider will not happen until after the conclusion of a consultation on its forthcoming Green Paper on a Bill of Rights for Britain. We consider that this presents a significant retreat from the Government’s earlier commitment to provide a solution for private care homes as soon as possible. We are concerned that this change of view will leave a significant gap in the protection of vulnerable people receiving support in the private sector, including adults with learning disabilities. We recommend that the Government legislate to ensure that all private providers of health and social care are considered public authorities for the purpose of the Human Rights Act and are subject to the duty to comply with Convention rights. (Paragraph 292)

### Conclusions: Putting human rights principles into practice

78. Although we were impressed by the passion for a human rights based approach expressed by the Minister for Care Services and the Minister for Disabled People, we are persuaded that real change for adults with learning disabilities will only happen if practical steps are taken to promote a more positive approach to the rights of adults with learning disabilities on the ground, in mainstream public services. (Paragraph 295)
79. Public authorities should never be allowed to treat their duties towards adults with learning disabilities under the Human Rights Act 1998 and the Disability Discrimination Act (including their positive duties under the Disability Equality Duty) as optional. (Paragraph 296)
80. We urge the Department of Health and the Office for Disability Issues to consider opportunities for joint-working to meet the aims of *Valuing People* and *Valuing People Now*. As part of this process, we recommend the amendment of *Valuing People Now*, to remind all public authorities, including Government Departments, local authorities and NHS Trusts, that the aim of the Government’s policy is grounded both in the need to respect the human rights of adults with learning disabilities, and in the binding obligations of the Human Rights Act 1998 and the Disability Discrimination Act (as amended). We consider that this would send a strong message to mainstream services that implementation of this policy is not optional. (Paragraph 301)
81. We consider that the Equality and Human Rights Commission has a crucial role to play in the creation of a broad culture of human rights. (Paragraph 303) We encourage the Equality and Human Rights Commission to ensure that it monitors the performance of the Government and other public bodies in relation to the treatment of adults with learning disabilities, and take steps, including through active involvement with their statutory Disability Committee or otherwise, to ensure that adults with learning disabilities play a central role in its work and that their views and voices are heard. (Paragraph 303)

## Annex 1: Relevant human rights laws and standards

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1. The treatment of adults with learning disabilities raises clear human rights issues. In this Annex we set out the key human rights standards, deriving from common law, UK statutes and international treaties and explain how they are applicable to this inquiry.<sup>448</sup> We recognise the important relationship between human rights and human rights law, such as the important protection offered by the Human Rights Act 1998 and legislation designed to promote equality and non-discrimination. We summarise briefly, the provisions of the Disability Discrimination Act 1995 (as amended), including the Disability Equality Duty, and the Mental Capacity Act 2005, both of which are directly relevant to the lives of adults with learning disabilities.

2. In this report we refer to ‘human rights principles’. By this we mean the concepts of ‘fairness’, ‘respect’, ‘equality’, ‘dignity’ and ‘autonomy’. These are examples of the fundamental principles or core values on which all human rights treaties and other instruments are based. We also refer to a ‘human rights based approach’ in relation to the work of public authorities. In essence this involves public authorities considering their policies and practices through a human rights lens, in other words taking the principles and human rights standards and applying them to the organisation’s objectives and day-to-day activities to assess whether they comply with such principles and standards. The Department of Health and the British Institute of Human Rights describe a human rights based approach in the following way:

In essence a human rights based approach is the process by which human rights are put into practice. It has five key principles:

- Putting human rights principles and standards at the heart of policy and planning
- Empowering staff and patients with knowledge, skills and organisational leadership and commitment to achieve human rights based approach.
- Enabling meaningful involvement and participation of all key stakeholders.
- Ensuring clear accountability throughout the organisation
- Non discrimination and attention to vulnerable groups.<sup>449</sup>

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<sup>448</sup> We included a similar Annex in our Report on the Human Rights of Older People in Healthcare. In that Annex, we discuss the application of the Human Rights Act 1998 and the common law on for humane treatment, dignity and equality in greater detail. *Eighteenth Report of Session 2006-07, The Human Rights of Older People in Healthcare*, HL Paper 156-1, HC 378-1.

<sup>449</sup> *Human Rights in Healthcare – A Framework for Local Action*, Section 0.1.

## Common law principles

3. There are important principles that derive from our common law and are now embodied in human rights and equality legislation:

Under the common law, the state is required to treat people humanely. In addition, the courts recognise a common law principle of equality. The corollary of the principle of equality is the requirement not to discriminate either directly or indirectly without objective and reasonable justification.<sup>450</sup>

4. There is increasing evidence of the development of a common law principle of respect for human dignity, emerging from human rights and other jurisprudence.<sup>451</sup> We consider that all of these common law principles are relevant to this inquiry and to the treatment of adults with learning disabilities by our society.

## Human Rights Act 1998

5. The Human Rights Act 1998 (HRA) came into force in October 2000. It incorporates the main rights and freedoms set out in the European Convention on Human Rights into UK law.

6. The HRA requires that all public authorities act in a manner which is compatible with the rights set out in the ECHR. If public authorities fail to meet this duty, people who are affected by the breach may ask the courts for a remedy. Public authorities include central Government, local authorities, NHS Trusts, and most providers of public services. Unfortunately, the Court has decided that certain private bodies which provide services to vulnerable people, including in residential care homes, are not public authorities because they do not perform “public functions”.<sup>452</sup> More information about legal responsibilities of public authorities under the Human Rights Act can be found in our Report on older people in healthcare.<sup>453</sup>

## Convention rights

7. All of the rights set out in the ECHR apply to people with learning disabilities. It is unlawful for public authorities to act in a manner which is incompatible with the ECHR rights set out in the Human Rights Act. We have set out below the articles that are particularly relevant to the issues raised in this inquiry.

### *Right to life (Article 2)*

8. In addition to prohibiting the intentional and unlawful taking of life, States are under a positive duty to take appropriate steps to protect life. Article 2 will also be engaged in

<sup>450</sup> Eighteenth Report of Session 2006-07, *The Human Rights of Older People in Healthcare*, HL Paper 156-I, HC 378-I, Annex, Page 80, para 2.

<sup>451</sup> *Ibid*, paras 27 – 33.

<sup>452</sup> *YL v Birmingham City Council* [2007] 3 WLR 112.

<sup>453</sup> Annex, paras 3 – 19.

circumstances where an individual's life is known (or ought to be known) to be at a real and immediate risk but the State fails to take reasonable steps to avoid that risk.<sup>454</sup>

9. The circumstances leading to the deaths of the six people with learning disabilities described in Mencap's report, *Death by Indifference* are likely to engage Article 2. During this inquiry we received evidence raising similar concerns that people with learning disabilities had died following the failure of health services to diagnose, or respond appropriately to, the person's health problems. (Article 2, Right to life).

### **Freedom from torture or inhuman or degrading treatment or punishment (Article 3)**

10. To fall within this Article the treatment given to a person must attain a 'minimum level of severity'. This will depend on the circumstances of the case, such as the duration of the treatment, its physical or mental effects and, in some cases, the sex, age and state of health of the victim.<sup>455</sup> Even if the treatment does not amount to a violation of Article 3, it may violate the right to autonomy and dignity under Article 8 (see below).<sup>456</sup>

11. Although the European Court of Human Rights usually requires that there has been an intention to humiliate and debase the person concerned, this is not always necessary.<sup>457</sup> Furthermore, Article 3 may give rise to positive obligations on States, requiring them:

[...]to take measures designed to ensure that individuals within their jurisdiction are not subjected to torture or inhuman or degrading treatment, including such ill-treatment administered by private individuals.<sup>458</sup>

12. In this inquiry we were given examples of the way in which people with learning disabilities are treated. The following examples could amount to a violation of Article 3 (in addition to violations of other ECHR articles):

- use of physical restraints (Article 8 ECHR is also likely to be engaged);
- blanket policy of dentist to remove all the teeth of patients with Down's syndrome
- failure to protect from physical assaults by co-resident of home (Article 8 is also likely to be engaged).

### **Right to liberty (Article 5)**

13. This right aims to protect individuals from arbitrary detention. Individuals can only be detained in the limited circumstances specifically set out in the article, for example

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<sup>454</sup> *Keenan v United Kingdom* [2001] 3 EHRR 913.

<sup>455</sup> *Selmouni v France* [1998] EHRLR 510, paragraph 100.

<sup>456</sup> *Wainwright v the UK* [2006] ECHR 807

<sup>457</sup> *Price v UK* [2002] 34 EHRR 53

<sup>458</sup> *Z and others v UK* (2002) 34 EHRR

following a lawful conviction for a criminal offence, or on the basis of the person's 'unsound mind'.<sup>459</sup>

14. A recent case demonstrates the relevance of Article 5 to the care and treatment of people with learning disabilities. In October 2005 the European Court of Human Rights held that there were insufficient safeguards for people who lacked capacity to agree to their informal admission to psychiatric hospitals. The Court found that the applicant, who lacked capacity to agree to his admission to hospital, had been deprived of his liberty contrary to Article 5(1) ECHR because his admission was not 'prescribed by law'. It was also contrary to Article 5(4) because he was unable 'to take proceedings by which lawfulness of his detention shall be decided speedily by a court'.<sup>460</sup> As a result of this decision, the Mental Capacity Act 2005 has been amended to include procedures to authorise the deprivation of liberty of individuals who lack capacity to decide whether or not they should be resident in a hospital or care home.<sup>461</sup>

### **Right to a fair hearing (Article 6)**

15. This Article relates to both civil and criminal proceedings, requiring that individuals have access to a fair and public hearing within a reasonable period of time before an independent and impartial tribunal or court. During the course of this inquiry numerous concerns have been raised, that children of people with learning disabilities are more likely to be removed from their parents' care than people without learning disabilities. We were also told that there is a lack of independent advice and legal representation in child care proceedings. This is an example of an issue which may raise questions about compliance with Article 6.

### **Right to respect for private and family life, home and correspondence (Article 8)**

16. This covers a wide range of areas affecting individuals' daily lives, such as parents' access to their children, compulsory treatment and medical examinations. Any interference with this right must be justified under one of the grounds set out in Article 8(2) such as public safety, the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.' Thus while there may be circumstances in which the intervention is justified, those involved in this decision would need to ensure that there were lawful grounds for the interference and it was proportionate to the risk identified.

17. There may also be circumstances in which the state is under a positive obligation to ensure respect for private and family life, for example, the right to respect for private and family life may give rise to a positive obligation to take steps to ensure that the individual can lead as normal a private or family life as possible.

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<sup>459</sup> *Winterwerp v the Netherlands* [1979] 2 EHRR 387.

<sup>460</sup> *HL v UK* [2004] 40 EHRR 761.

<sup>461</sup> See Section 50 and Schedules 7 – 9, Mental Health Act 2007.

18. An example of how these positive obligations may affect people with complex needs and profound learning disabilities can be found in a case concerning the way in which two severely disabled sisters were cared for by local authority carers. The Court found that Article 8 required protection of the sisters' dignity, and that this would require positive steps on the part of the State to enable the sisters to be lifted manually.<sup>462</sup>

19. In this inquiry we have heard of a range of ways in which people with learning disabilities' right to private and family life under Article 8 may be infringed. For example:

- being patronised, harassed and bullied (Articles 8 and 14 (right to non-discrimination in the exercise of ECHR rights));
- restrictions imposed by family or staff on developing personal relationships (Article 8);
- being given no choice about where to live (Article 8, Right to private and family life);
- personal correspondence is opened and read by staff (Article 8);
- contact with family is severed due to out of area placement (Article 8);
- treatment is given without consent being sought first (Article 8).

### **Prohibition on discrimination (Article 14)**

20. The rights protected by the ECHR must be guaranteed without discrimination. This right is violated when States treat differently persons in an analogous situations without providing an objective and reasonable justification. It also applies where States fail to treat people differently when their circumstances require special, or different, treatment:

The right not to be discriminated against in the enjoyment of rights guaranteed under the Convention is also violated when States without an objective and reasonable justification fail to treat differently persons whose situations are significantly different.<sup>463</sup>

21. For example, we were told of incidents in which the provision of health care was denied because the person had a learning disability. Such cases are likely to engage Article 8 together with Article 14. There may also be circumstances in which such refusal to provide healthcare engages Article 2 (the right to life) and Article 3 (freedom from inhuman and degrading treatment).

### **Disability Discrimination Act 1995 (as amended)**

22. An important factor in considering the opportunities of adults with learning disabilities to access public services and to participate in the community without discrimination is the scope and application of the duties set out under the Disability Discrimination Act 1995 (as

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<sup>462</sup> *A and B (X and Y) v East Sussex CC* [2002] EWHC 2771 (Admin).

<sup>463</sup> *Thlimminenos v Greece* [2000], 31 E.H.R.R. 411.

amended). This Act makes it unlawful to discriminate against a disabled person in a range of areas, including employment and the provision of goods and services. The Act places employers and providers of goods and services under a duty to make “reasonable adjustments” to their usual practices in order to avoid discriminating against people with disabilities, including learning disabilities. The Code of Practice on Rights of Access (2006) describes the imposition of this duty on service providers as “a cornerstone” of the Disability Discrimination Act. The Code explains:

It requires service providers to take positive steps to make their services accessible to disabled people. This goes beyond simply avoiding treating disabled people less favourably for a disability related reason.<sup>464</sup>

23. The Code explains that service providers must take a positive approach to the duty:

The policy of the Act is not a minimalist policy of simply ensuring that some access is available to disabled people; it is, so far as is reasonably practicable, to approximate the access enjoyed by disabled people to that enjoyed by the rest of the public. Accordingly, the purpose of the duty to make reasonable adjustments is to provide access to a service as close as it is reasonably possible to get to the standard normally offered to the public at large.<sup>465</sup>

24. The Disability Discrimination Act 2005, which amends the earlier Act, introduces a general duty on public authorities to promote disability equality. We refer to this duty as the ‘Disability Equality Duty’. The Disability Equality Duty requires all public authorities, when carrying out their functions, to have ‘due regard’<sup>466</sup> to the need to:

- eliminate unlawful discrimination against disabled people;
- eliminate disability-related harassment of disabled people;
- improve equality of opportunity of disabled people between disabled people and others;
- take steps to take account of disabled persons’ disabilities even where that involves treating disabled people more favourably than other persons;
- promote positive attitudes towards disabled people;
- encourage participation by disabled people in public life.

25. The Disability Discrimination Act 2005 also places a duty on some public authorities, including NHS bodies and local authorities, to publish a ‘Disability Equality Scheme’, in which the authority sets out how it intends to fulfil its Disability Equality Duty. Public authorities must involve disabled people in preparing these schemes. These new duties

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<sup>464</sup> para 6.3.

<sup>465</sup> para 6.4.

<sup>466</sup> See paragraphs 2.34-2.44 The Duty to Promote Disability Equality: Statutory Code of Practice for a discussion on the meaning of ‘due regard’. Paragraph 2.34 states: ‘In all their decisions and functions authorities should give due weight to the need to promote disability equality in proportion to its relevance. This requires more than simply giving consideration to disability equality.’

therefore introduce significant changes to the purpose and scope of the disability discrimination legislation:

The new legislation will mark a shift from the reactive duties of DDA 1995 towards a positive duty to actively promote equality of opportunity for disabled people. The new Act is based on the belief that the disadvantage and social exclusion which is often experienced by disabled people is a consequence of environmental barriers. These can take the form of inaccessible buildings, but are also found in employment practices or services which do not take the particular circumstances of disabled people into account.<sup>467</sup>

### ***Disability Equality Duty and the promotion of equality of opportunity***

26. The aim of the disability equality duty is to ensure that consideration of the needs of disabled people becomes an integral part of the policy-making or decision making process. The overarching goal is to achieve equality of opportunity:

The objective is that disabled people should have full opportunities and choices to improve the quality of their lives, and be respected and included as equal members of society.<sup>468</sup>

27. Public authorities are expected to take a proactive approach and to tackle the consequences of decisions, which in the past failed to give due regard to disability equality. The Disability Discrimination Act 1995 (as amended) recognises that to achieve equality of opportunity requires more than treating disabled people the same as everyone else, and that it is sometimes necessary to take positive steps to overcome the barriers faced by disabled people, by making reasonable adjustments.<sup>469</sup>

### **The Mental Capacity Act 2005**

28. The Mental Capacity Act 2005, which came into force in October 2007, should also have a significant impact on many adults with learning disabilities. This Act provides a legal framework for acting and making decisions on behalf of individuals (aged 16 or over) who are unable to make such decisions for themselves. It covers a wide range of decisions, both personal (health and welfare) and relating to finance and property. Individuals' capacity must be assessed in relation to their capacity to make a particular decision at the time it needs to be made.

29. Significantly for people with learning disabilities, who are often assumed to lack capacity, the Mental Capacity Act's starting point is the presumption that everyone has legal capacity to take their own decisions:

<sup>467</sup> Creating a Disability Equality Scheme: A Practical Guide for the NHS, Department of Health, October 2006 [www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/documents/digitalasset/dh\\_4139668.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4139668.pdf).

<sup>468</sup> For further information see the Mental Capacity Act 2005, Code of Practice, February 2007, available at: [www.justice.gov.uk/whatwedo/mentalcapacity.htm](http://www.justice.gov.uk/whatwedo/mentalcapacity.htm). Guides on the MCA are also available at: [www.dca.gov.uk/legal-policy/mental-capacity/index.htm](http://www.dca.gov.uk/legal-policy/mental-capacity/index.htm).

<sup>469</sup> Creating a Disability Equality Scheme: A Practical Guide for the NHS, Department of Health, October 2006 [www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/documents/digitalasset/dh\\_4139668.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4139668.pdf).

It should be assumed that an adult (aged 16 or over) has full legal capacity to make decisions for themselves (the right to autonomy) unless it can be shown that they lack capacity to make a decision for themselves at the time that the decision needs to be made.<sup>470</sup>

30. In addition to the presumption of capacity, the Mental Capacity Act 2005 requires that a person is not to be treated as unable to make a decision, unless all practical steps to help the person make the decision have been taken. Where the person is judged to lack capacity to make the particular decision, the decision made on that person's behalf must be made in that person's best interests. Before an act or decision is taken on behalf of a person who lacks capacity, consideration must be given as to whether the same purpose can be achieved as effectively, in a manner that is less restrictive of the person's rights and freedom of action.<sup>471</sup>

31. The Mental Capacity Act 2005 creates a new specific independent advocacy service, referred to as the Independent Mental Capacity Advocate (IMCA) service. NHS bodies and local authorities must make sure that IMCAs are available to represent and support those people who lack capacity to make important decisions about serious medical treatment and changes of accommodation and do not have relatives or friends who would be appropriate to consult about those decisions. IMCAs may also be involved in decisions concerning care reviews and adult protection cases.<sup>472</sup>

## UN Convention on the Rights of Persons with Disabilities

32. The UN Convention on the Rights of Persons with Disabilities<sup>473</sup> builds on existing human rights treaties including the International Covenant on Civil and Political Rights and the International Covenant on Economic Social and Cultural Rights. Its purpose is to:

promote, protect and ensure the full enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.

33. Article 1 sets out the general principles of the Convention which include: 'non-discrimination', 'equality of opportunity', 'respect for difference and acceptance of persons with disabilities as part of human diversity and humanity' and 'full and effective participation of persons'. The first principle is that there shall be:

Respect for the inherent dignity, individual autonomy, including the freedom to make one's own choices, and independence of persons.

33. The UN Disability Rights Convention covers a mixture of civil and political and economic, social and cultural rights. These include equality and non-discrimination

<sup>470</sup> Mental Capacity Act, Code of Practice 1.2.

<sup>471</sup> Section 1(6) Mental Capacity Act 2005.

<sup>472</sup> For further information see Chapter 10 Mental Capacity Act 2005 Code of Practice and 'Making decisions: The Independent Mental Capacity (IMCA) service', [www.dca.gov.uk/legal-policy/mental-capacity/mibooklets/booklet06.pdf](http://www.dca.gov.uk/legal-policy/mental-capacity/mibooklets/booklet06.pdf).

<sup>473</sup> The Convention was adopted on 6 December 2007. UN General Assembly, Sixty-First Session A/61/611.

(Article 5), the right to life (Article 10), respect for privacy (Article 22), respect for home and the family (Article 23), the right to education (Article 24) and the right to the enjoyment of the highest attainable standard of health (Article 25). Article 19 provides for the right of 'living independently and being included in the community'.

35. States are expected to be proactive in ensuring respect for the rights set out in the UN Disability Rights Convention. For example, Article 4 requires States to take steps to '...ensure and promote the full realization of all human rights and fundamental freedoms' of disabled people 'without discrimination of any kind on the basis of disability.' A wide range of actions is listed. These include adopting legislative and other measures for the implementation of the rights under the UN Disability Rights Convention and modifying existing laws, regulations and practices that constitute disability discrimination. When undertaking such work, governments will be required to 'consult closely with and actively involve' disabled people. Governments will also be required to promote training on the UN Disability Rights Convention for staff and professionals who work with disabled people.

36. To date, 123 States have signed this treaty (including the UK) and 13 States have ratified this Convention. It is anticipated that in the next year or so it will come into force once the requisite number ratifications has been achieved (20 States). Anne McGuire, MP, Minister for Disabled People, informed us that the UK Government intends to ratify the Disability Convention by the end of 2008, if not before.

37. An Optional Protocol to the UN Disability Rights Convention provides for individuals to submit complaints about alleged violations of their rights under Convention to the Committee on the Rights of Persons with Disabilities.

38. Although ratification of the UN Disability Rights Convention will not incorporate it into domestic law, this Convention has the potential to be highly influential. For example national courts and the European Court of Human Rights regularly refer to international human rights treaties to assist in the interpretation of the ECHR and may therefore use the UN Disability Rights Convention for this purpose in relation to disability issues.

## **Themes arising from human rights standards and legislation**

39. The following themes emerge from the human rights standards and legislation discussed above and are relevant to people with learning disabilities.

### ***Positive obligations to promote human rights and equality***

40. Human rights standards are not just about requiring states to refrain from interfering with individuals' human rights or ensuring that where rights have been infringed, appropriate legal redress is available. In certain circumstances States are also required to take action in order to ensure that individuals' rights are protected. This is of crucial importance because during this inquiry we have been given many examples of how people with learning disabilities are excluded from society (these barriers are discussed in Chapter 8).

41. Both the ECHR and the Disability Discrimination Act 1995 (as amended) require that public authorities be proactive in certain cases if they are to comply with their statutory

duties. For example, in relation to the Human Rights Act, Articles 2, 3, 5 and 8 of the Convention can give rise to obligations on States ‘to take appropriate steps to provide protection against an interference with those rights either by State agents or by private parties.’<sup>474</sup> This positive obligation was considered by the High Court in a case concerning two sisters with profound physical and learning disabilities. The court commented that Article 8 encompasses:

[...] the positive obligation of the State to take appropriate measures designed to ensure to the greatest extent feasible that a disabled person is not “so circumscribed and so isolated so to be deprived of the possibility of developing his personality”<sup>475</sup>.

42. In the case of the Disability Discrimination Act 1995 (as amended), the Disability Equality Duty specifically allows a public authority to treat disabled people more favourably in order to achieve equality of opportunity. The Disability Equality Duty Code provides the following example:

An authority is involving disabled people in identifying the main barriers which they experience in relation to its functions, but has been unable to engage many people with learning disabilities. Following discussions with a representative organisation of people with learning disabilities, it becomes apparent that some people with learning disabilities are unable to become involved without the support of advocates. The authority provides funding for advocates to be employed to support people with learning disabilities at an event which the authority holds as part of its involvement processes, as well as ensuring that the process is accessible by, for example, providing Easy Read documentation.<sup>476</sup>

### ***Equality and human rights – equality of opportunity***

43. Equality of opportunity is one of the UN Disability Rights Convention’s key principles. It is also reflected in UK disability discrimination legislation through, for example, the Disability Equality Duty.

### ***Promoting participation***

44. Participation is a core theme of the UN Disability Rights Convention. For example:

- one of its general principles is ‘Full and effective participation and inclusion in society’ (Article 3 (c));
- Article 19 provides for ‘Living independently and being included in the community’;

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<sup>474</sup> *Storck v Germany* 2005.

<sup>475</sup> *A and B (X and Y) v East Sussex CC* [2002] EWHC 2771 (Admin), paragraph 99. See also *Price v the United Kingdom* (2001) 34 EHHR 1285 and *Botta v Italy* (1998) 26 EHHR 241.

<sup>476</sup> The Duty to Promote Disability Equality: Statutory Code of Practice, para 2.16.

- Article 26 requires states to take effective measures to enable disabled people to ‘attain and maintain maximum independence...and full inclusion and participation in all aspects of life;
- Article 29 provides for ‘Participation in political and public life’. This includes ensuring that ‘voting procedures, facilities and materials are appropriate, accessible and easy to understand and use’.

45. Article 8 of the ECHR also incorporates issues relevant to participation, for example it encompasses the right to participate in the life of the community. Participation covers the involvement of individuals that affect them personally as well as decisions relating to policy development. The European Court of Human Rights has recognised that freedom to exercise control over our own lives is a key aspect of Article 8:

Although no previous case has established as such any right to self-determination as being contained in Article 8 of the Convention, the Court considers that the notion of personal autonomy is an important principle underlying the interpretation of its guarantees.<sup>477</sup>

46. Article 26 of the European Union’s Charter of Fundamental Rights provides for the ‘integration of persons with disabilities’. It states:

The Union recognises and respects the right of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community.

47. Although this Charter is not legally binding it has been referred to by the courts when considering the scope of Article 8 ECHR.<sup>478</sup>

### ***Challenging negative assumptions, stigma and discrimination***

48. Article 8 of the Disability Rights Convention provides for awareness raising. It requires states to ‘adopt immediate, effective and appropriate measures’ such as promoting awareness of the capabilities and contributions of disabled people, and to combat stereotypes prejudices and harmful practices. Article 16 requires states to take measures to protect disabled people ‘both within and outside the home from all forms of exploitation, violence and abuse’.

49. The requirement on States to take positive measures to protect the rights of individuals that in certain circumstances arise under Articles 3 (freedom from torture, inhuman or degrading treatment or punishment) 8 (right to private and family life) and Article 14 (freedom from discrimination in the exercise of ECHR rights) are also relevant here.<sup>479</sup>

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<sup>477</sup> *Pretty v the United Kingdom* [2002] 35 EHRR 1.

<sup>478</sup> See for example, *R (on the application of A and B) v East Sussex CC* [2003] 6 CCLR 194.

<sup>479</sup> See the discussion on positive obligations to promote human rights and equality above.

## Annex 2: Contributions to the inquiry from members of the public

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1. We received a significant number of submissions from members of the public, including people with learning disabilities and their families or carers and professionals working in the field of learning disabilities. Some of these submissions have been published as part of a separate volume of evidence. However, a number of submissions gave examples of individual cases and enclosed correspondence about those cases. Some submissions included copies of our call for evidence, in Easy Read, with hand-written additions and comments. Some people have asked for anonymity or for their submissions to remain private. We have not published such submissions but instead offer a summary of the main points they raise.

### Themes and concerns

2. A number of themes and concerns were raised in the correspondence we received from the public, including:

- A lack of understanding towards people with learning disabilities, by service providers and in the wider community;
- Discrimination, abuse and bullying;
- Access to funding for services and support;
- Gap between policy in *Valuing People* and reality;
- Importance of advocacy and Easy Read information;
- Supported or independent living (including access to housing and employment);
- Human rights, education and training.

3. These themes are explored in more detail below. We also received a number of submissions from people with learning disabilities who told us that although they are happy with their lives, there are other people with more complex needs or more profound learning disabilities who may not be.

### *A lack of understanding for people with learning disabilities*

4. A number of submissions referred to the lack of understanding towards people with learning disabilities. These discussed a range of negative attitudes ranging from fear, bullying and dissociation to misunderstanding and unhelpful stereotyping. See for example:

She feels useless and is bullied – she always gets the blame if anything goes wrong. They are not used to working with people with learning difficulties. [She] needs to be shown (sometimes a number of times) before her brain registers any new tasks. She is determined to live independently and has a constant struggle to be accepted.

*A parent of an adult with learning disabilities discusses her daughter's experiences.*

[Our local Mencap] was preparing to purchase a 5-bedroom house in a local estate for four people to live in with overnight sleep-in cover. The local community learnt about this and a large group requested a meeting with our Chairman. He said it was the nastiest group he had ever been confronted by. They expressed their strong objections to the purchase.

*A parent of an adult with learning disabilities and Trustee of local Mencap group.*

### **Discrimination, bullying and abuse**

5. A number of submissions referred to discrimination, bullying and abuse. These range from submissions on discrimination faced by adults with learning disabilities in their attempts to participate in the community to stories of physical and sexual abuse, by carers or by others, including other people with learning disabilities.

I moved to [a new home] where, when people were bad the staff said that they could not stay up. I was there 8 years. I used to run away – it was hell there it was like a prison. I had to go to bed at 6 o'clock and missed the soaps. Other people had boyfriends. I had two breakdowns because of it...They treated me like dirt. In my thirties, I lived at Mill Road. I had another breakdown as again people would not let me do what I wanted to do.

*A person with learning disabilities describes her previous experiences.*

I answered a phone call from [the police force local to my son's school], who told me they suspected [my son] and two other pupils at [his school], had been sexually assaulted, and that they were passing the case onto [our local police] – which they did. Although [our local police] were sympathetic they categorically refused to interview [my son]. This was because he had mental health issues and extreme challenging behaviour.

*Mother of an adult with learning disabilities.*

Some people take the mick out of me and I used to get bullied, but I know people know about my learning disabilities ... my girlfriend does not have a learning disability. She gets treated fairly more than me because I have a learning disability. People laugh at her when she is with m, but she just says he is the same as any one else.

*A person with learning disabilities describes his previous experiences.*

Making this work is down to attitudes, and, as many of the group members are over 50, they were brought up in a time when people thought very differently about what is possible if you have a learning disability. Parents were given very different advice and information and maybe people's hopes were pitched a bit lower.

*Summary from a submission from a small self advocacy group.*

As a carer I have found that judgmental attitudes are a barrier to good planning. As a family carer I would have to 'field' not only my son's distress but the attitudes of those who are supposed to help. People are too quick to judge 'a behaviour' without the knowledge of the disability.

*A parent of an adult with learning disabilities describes his concerns.*

I'm the one

Are you listening?

I'm the one that school described as hopeless

I'm the one that you described as friendless

I'm the one that kids described as useless

I'm watching

You're the one who writes my care plan

She's the one that limits my pocket money

You're the one that manages my lifestyle

He's the one who controls what I watch on TV

You're the one who tells me I have a choice

They're the ones that write my menu

You're the one that insists I explore my inappropriate behaviour

He's the one that swears at me

Is there anyone there?

Because I'm the one whose life you're supporting

I've the one you are paid to care for

I'm the one who is a challenge

Because I'm the one who is asking you to listen

*Poem written by Champions*

*A Group of Trainers on Abuse, who are also People with Learning Disabilities.*

### ***Access to funding for services and support***

6. A significant number of submissions focussed on funding, access to services and support. These covered areas including:

- adequacy of assessment by Social Services and difficulties in relationships with local councils;

Poor assessment leads to poor care plans leading to incorrect funding. Assessments seem less to do with person centred plans and the individual than with cost cutting. ... Assessed and written in many cases by 'professionals' with little knowledge and training.

*A family carer expresses her concerns.*

- overcomplicated systems for accessing benefits;
- difficulties associated with access to direct payments, or other support. For example;

It annoys me when I hear the Government saying that people are not claiming all the money that they are entitled to because time after time we have had to fight, sometimes reapplying three times before we have got the allowances we were entitled to.

*A family carer expresses her concerns.*

When group members can't do something they want to or that is important to them, it is usually not because people don't respect their rights but is usually down to lack of staff or other support or having no transport.

*Summary from a submission from a small self advocacy group.*

- eligibility criteria and exclusion from service provision;

We are concerned the drift away from local community support is showing signs of a return to an institutional mind set and that a person with learning disabilities is losing the basic human right of respect and access to services.

*Chair of a local action group expresses her concerns.*

- closure of existing services;

Surely it is an infringement of their human rights to take their facilities away from them without consultations and without any alternatives in place, it has been said that the private sector will provide day centres and facilities, but at present, there are not private sector facilities available at all.

*Person involved in a local campaign against day centre closures.*

- inability to access care and support in health and social care, including in hospitals. For example;

I have been advised by carers [that] nursing staff on wards do not provide adequate care to ensure that adults with learning disabilities are able to go to the toilet, have access to food and water and in very rare circumstances pass [on] important information [...]

*A submission on standards in healthcare.*

In the past when we've used our GP we found we were not listened to or even believed. We had to persist and the community nurses helped get us referred to the hospital.

*A family of people with learning disabilities.*

When I go to the doctors or to hospital they always talk to my mum about what is wrong and not me. The dentist is better he talks to me as well as my mum. I think they would all tell me what is happening.

*A learner from Linkage Community Trust expresses their views.*

I am not happy because the government are not doing their jobs properly because the doctors are not talking to me as a person because I have special needs.

*A person with learning disabilities expresses her view.*

Each time he has been in hospital I or my husband has had to stay with him as the care he requires is not provided in local hospitals. Also there are no facilities (slings/hoists/changing bed) to help with his personal care, he is doubly incontinent. In hospital he has to spend all day in bed as there is no way of transferring him to a chair/wheelchair.

*A parent of an adult with learning disabilities describes her experiences.*

### ***The gap between the policies in Valuing People and reality on the ground***

7. Although the policies in *Valuing People* could in principle lead to respect for the human rights of adults with learning disabilities, the reality is far from the ideal envisaged by the Government's policy. This was reflected in some of these submissions:

From my own personal experience, I am convinced, that any legislation or procedures brought in to enhance the Human Rights of Adults with a Learning Disability will only be as effective as the Support Worker at the sharp end, on duty at that time.

*Support Worker, Mencap.*

While the situation for many people with learning disabilities has improved dramatically over the last twenty years, there is still a long way to go before they will be in a situation which parallels that of most other members of the community. The White Paper *Valuing People* was full of excellent recommendations, many of which have either been paid lip service, or have been ignored completely. There is a feeling amongst professionals that it was a lot of rhetoric without legislative teeth to ensure that its recommendations would be put into practice. There is still a huge gap between what was recommended and what actually happens.

*An NHS Clinical Psychologist in Learning Disability Services.*

*Valuing People* was a document that amongst other things states “nothing about us without us”. Unfortunately despite the guidance given in this white paper, in my view, implementation has been patchy and there seems to be a lack of commitment within services to change the way they work

*A parent of an adult with learning disabilities expresses his views.*

The White Paper *Valuing People* talks about the importance of community presence and participation, but £1.75 per week to spend is not enough to enable anyone to do that.

*A parent of an adult with learning disabilities expresses her views.*

### **Importance of advocacy and Easy Read information**

8. We heard significant evidence on the importance of access to Easy Read information and to the services of an independent advocacy service. A number of these submissions also address these issues:

I think we don't get enough help when filling in council forms because I don't understand the forms. This makes me feel very frustrated because I am a non reader with learning difficulties. I feel that social services do not make things easy for me. My social worker bosses me around and does not include me in decision making, this may be because I don't like saying anything because he makes me feel stupid ... This makes me feel that I am not treated fairly as an adult.

*A learner from Linkage Community Trust expresses their views.*

As an elderly carer now, I would also like to promote the concept of individual advocates for those in residential care, at the moment we ensure that the provision is good, but when we are no longer around, someone who is actively independently concerned with my daughter's quality of life is of paramount importance, so could this also be part of your considerations.

*A parent of an adult with learning disabilities expresses her views.*

What would help people with learning disability get their human rights? More self advocacy workers to help people speak up for themselves; more representational advocates to take up specific cases and act on peoples behalf; more investment in getting the right sort of information out there in a form that people understand

*Submission on behalf of two people with Learning Disabilities*

### **Supported or independent living**

9. A number of submissions focused on the barriers adults with learning disabilities met when seeking to live independently or to play an active part in their community. These related to:

- inability to access appropriate supported housing;

- employment and education;

Being a contributing member of one's local community doesn't just mean going to the local, mainstream leisure centre or buying one's own groceries; it should mean the opportunity to do meaningful, paid, work, for those who want to and are able.

*Mother of an adult with learning disabilities expresses her views.*

- inability to access day activities or appropriate residential care, or respite care for carers;
- supporting people with learning disabilities to form relationships with family, friends boyfriends and girlfriends and their children;

[Her] father and I now supplement [her] income, in order to enable her to participate in community life, and maintain her friendships. Without our help, [she] would have a life of poverty, and social isolation.

*Mother of an adult with learning disabilities on her daughter's experiences.*

I think it is harder for the learning disability person who is gay.

*A learner from Linkage Community Trust expresses their views.*

We are unable to go far as there are no disabled toilets in which to attend to his needs. So as a family we are all restricted in the participation in the local community. He is unable to meet with friends or socialise and without us taking him for a local walk or a short drive in his van we would be completely isolated.

*Mother of an adult with learning disabilities on her family's experiences.*

Services are not supporting relationships. Families are regularly disrespected even in public arenas such as conferences. Family connections are not supported, families have to make all the running. For people with a learning disability, having ordinary relationships that involve sex (like everyone else) is not supported in fact often subverted or prevented.

*Mother of an adult with learning disabilities expresses her views.*

### **Human rights, education and training**

10. A number of submissions talked about human rights in terms of their relevance to people with learning disabilities, including where training and education had made a difference to the way that they had been treated. Some people thought that further training and education was needed to make people with learning disabilities and their support workers aware of their rights. See for example:

We don't know much about it and would like to learn more.

*Advocacy West Lancs.*

Training around rights would help people with a learning disability get their human rights. Twelve of the Forum Members sit on the Cornwall Learning Disability Partnership Board. They are called The Get Real Team. Have had training around rights and feel that it is easier to speak up

*Cornwall People First  
Bodmin Forum.*

I have recently left employment at a residential home for adults with learning disabilities. During my two years there and since leaving, I believe that these adults do not get to exercise their human rights in several aspects. They are not informed of their rights in a manner which they can understand, therefore are not aware that they have such rights.

*Former support worker expresses her views.*

I care for an adult with a learning disability and feel it is very important that his human rights are met and that he should be treated no differently in this respect to any other person.

*A carer expresses their views.*

People who have learning difficulties should have the same rights as any other person and the Government have rules in place to make this happen.

*A person with a learning disability expresses their views.*

Protecting the Human Rights of People with Learning Disabilities: This will not be achieved by rhetoric and fine words. Unless there is a way of giving the legislation some teeth, then changes will not occur.

*Consultant Clinical Psychologist*

11. We asked people for their views on the recent UN Convention on the Rights of Persons with Disabilities. A number of submissions commented on the ability of the UN Convention to make a difference to the way that people with learning disabilities are treated.

I don't know much about the convention on the human rights of people with disabilities but do feel very strongly that everyone with a disability should have equal rights to those whom don't have disabilities.

*A person with learning disabilities expresses his views.*

The Convention on the Rights of Disabilities can help them (and should help them) to have their rights – BUT, they must realise their special needs, which are different to other disabilities.

*A family with learning disabilities express their views.*

Most of the principles in the Convention are already stated in other places but it does pull everything together and really highlights that people with a learning disability have the same rights as everyone else.

*A small self advocacy group in Bedfordshire.*

## Annex 3: Note of Informal Meeting: 23 July 2007

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### Panel 1: Relationships, carers and support

Richard Jackson MBE, Founder and Honorary Chairman, Rescare.

Alison Giraud-Saunders, Co-Director, Foundation for People with Learning Disabilities.

Philippa Russell CBE, Disability Rights Commissioner and Disability Policy Adviser, National Children's Bureau and Viv Cooper, Chair of Trustees, The Challenging Behaviour Foundation, for the National Family Carers Network.

### *A human rights based approach*

#### *Awareness and human rights*

1. In response to questions about whether taking a human rights based approach to the provision of services for people with learning disabilities would make any difference, Alison Giraud-Saunders told the Committee that people with learning disabilities speak more about rights since the publication of *Valuing People*, but that they will talk more generally about 'rights', rather than specific human rights. Although this change in focus was clear, she was concerned that practical follow through was lacking. People with learning disabilities are not sure how to enforce their rights or are scared to press for their rights in case it will affect the services they receive. It would help if there was better access to advocacy services for people with learning disabilities.

2. Philippa Russell told the Committee that people with learning disabilities are concerned about rights and entitlements, but the concept of human rights is often expressed in a very abstract way. People with learning disabilities may use the language of 'rights', but may have an inexact view on what rights are and how to achieve them without access to appropriate information and an understanding of how 'human rights' inter-relate with rights and entitlements under other legislation. Although a lot more work needs to be done on implementation, the HRA and disability legislation can be used to give people enhanced rights and create positive expectations. She expressed her grave concern that, although the Disability Discrimination Acts had made significant improvements in people with learning disabilities' access to (and expectations of) services, the Disability Equality Duty on public services might be weakened if proposals within the Government's current consultation on the Discrimination Law Review were incorporated in the forthcoming Single Equality Act. Where the Disability Equality Duty works well, there is better awareness of rights by providers and recipients, because both are active partners in the development and delivery of the Disability Equality Scheme and related action plan to progressively improve the quality of the public service in question.

3. Richard Jackson told the Committee that while a human rights based approach is an important element in the 'care scenario', RESCARE is concerned for those people with severe and profound learning disabilities who are without capacity to make considered life affecting decisions or to activate rights on their own behalf. For them and their families, the new Mental Capacity Act 2005 will prove invaluable, with a parent or close family member able to apply to be appointed to the role of deputy to act on behalf of their dependent son, daughter or relative, including acting to ensure that they benefit from the protection of the various human rights instruments.

### *Human rights training*

4. Philippa Russell told the Committee that more training is needed for people with learning disabilities and their carers on the Disability Discrimination Act and HRA and how to use and maximise their potential. However, any training must be supplemented by regular updated information and by improved access to advice and advocacy services. She considered that misunderstanding and lack of information often negate the good intentions of human rights legislation.

### *Family carers and independent living*

5. Committee members asked about the role of family carers and service providers in supporting independent living. The Committee also asked whether family carers were likely to stand in the way of independent living for people with learning disabilities. The following points were made in discussion.

6. Philippa Russell noted that worrying about the safety of their children is common to all parents. She was confident that the vast majority of parents of people with learning disabilities are not over-protective and want a good life for their children, with maximum independence. She and her husband were committed to encouraging their son to develop maximum independence and to take sensible risks so that he could cope in adult life, in particular when his family were no longer able to support him. She thought that this approach was typical of most family carers. Often, if parents (whether parents of those with or without learning disabilities) sought to prevent their children from pursuing a particular course of action it would be well-intentioned and with a view to ensuring that their child did not follow a path that would lead them into danger. However, she felt that family carers and people with learning disabilities should be encouraged to be more ambitious about the future – particularly when planning for transition to adult life. She noted that she and her husband had 'fought tooth and nail' to enable their son to move out of a group home into a house of his own. The family was now supporting him in setting up a small business of his own. In effect, the family was determined to give him the same life chances enjoyed by his siblings but many families did not have the information, the opportunities or the encouragement to go down this road. She felt strongly that we should follow the example of the USA, where family carers and people with learning disabilities see each other as 'allies', working towards the common goal of 'ordinary lives'.

7. Viv Cooper told the Committee that currently there are some exciting developments in service provision, but that good provision and access to services are not typical. Often families would need to work very hard to achieve the appropriate care and services for their relative with learning disabilities. Although sometimes there is tension between family

members (i.e. between the person with learning disabilities and their family carer), working together as allies is the way forward.

8 Richard Jackson expressed the concern of RESCARE that not everyone with learning disabilities can live independently. RESCARE consider that the extent of their dependency is often overlooked in considering supported or independent living. Family input (70% of caring is within the family home) is very important and families have a prime role to play. For people with learning disabilities, the one stable lifelong relationship they have is with their families. This was acknowledged in *Valuing People*. RESCARE consider that this importance was further evidenced when the widespread abuse events in Cornwall's supported living service were brought to light by 5 families who refused to be intimidated and ignored.

9. He told the Committee about the effects of Fragile X syndrome on his family. He has a 57 year old son, two grandchildren and a great nephew with varying degrees of learning disability and/or autism. He stressed that he has a close and happy family, but that it is important to recognise that the needs of each of his relatives with learning disabilities are different. His family had to fight for each of their relatives with learning disabilities to get appropriate services. For example his great nephew after 3 years at a residential school, on leaving at 18 with no care planning or transfer to adult services after 3 days he was sectioned into the Acute Psychiatric Ward of the local General Hospital. After 18 months he was freed when the Ombudsman admonished the local authorities, fined them £30,000 and commended the perseverance of the family who challenged the authority.

10. The needs of each individual are different, but RESCARE consider that local authorities increasingly impose supported living and refuse funding or referrals to other options, and so, a dangerous "one size fits all" is developing. RESCARE agree that there should be supported living for those who can cope and respond but seek to have '*Valuing People*' and its choice in housing options implemented in full (i.e. small scale ordinary housing, supported living and village and intentional communities, as well as residential care). They were concerned that no option should be ruled out.

### *Independent living and care planning*

11. Philippa Russell stressed the need to have good quality person-centred planning for people with learning disabilities. Person-centred planning should actively involve people with learning disabilities and family carers and should focus upon improving life chances rather than on crisis intervention. She noted widespread concern about changes in the funding of further education and the loss of courses which had historically often enabled people with learning disabilities to acquire both skills for independent living and for vocational training and subsequent employment. She also noted growing concern at the 'postcode lottery' experienced by many families, with wide variations in the provision of high quality local services for people with complex disabilities. She emphasised the point that people with high individual support needs can live in local communities but the growing inappropriate use of 'out of area' provision for people with complex needs demonstrates the need for better investment at local level in developing a wider range of services. She also referred to a recent Disability Rights Commission/Guardian roundtable discussion on the future of social care, where local authorities argued that PCTs (Primary Care Trusts) were increasingly expecting local authorities to cover care costs which should

be joint funded. The Government's emphasis on commissioning for 'health and well-being' (i.e. joining up health and social care assessment and commissioning) was welcome, but there were currently wide variations in policy and practice.

12. She told the Committee that there needs to be more creative commissioning and a dynamic appraisal of what is meant by 'independent living'. It is not just about throwing people out into the community and currently most local authorities feel that their budgets are insufficient.

13. She regretted that the Independent Living Bill is unlikely to become law at this stage, but considers that this Bill could help make independent living a reality for many people with learning disabilities. Currently, there is not enough money given the rapid increase in the number of disabled people and children with complex needs. She highlighted a number of other issues which were currently overlooked in funding for care planning:

- More older people are caring for people with learning disabilities;
- More people with learning disabilities are themselves becoming carers, looking after children or supporting partners, parents or other relatives;
- Need for more investment in education for people with learning disabilities;
- Need to track children with learning disabilities through transition into adult life.

14. Often people only want something very small, but they are forced to ask for something bigger so that they can get it. In effect, more money is often spent on people in crisis, which could have been saved if an earlier service had been provided at a lower cost.

15. In considering independent living (which many people with learning and other disabilities consider to be a crucial human right), she drew attention to the Disability Rights Commission's definition of independent living.<sup>480</sup> She was concerned that 'independent living' was often viewed very narrowly, when in practice it meant people with learning disabilities (and their families) having the right to make active choices about where and how they wanted to live, with appropriate support. She also emphasised the importance of high quality support for family carers, so that they could be 'allies' in helping their relatives to achieve maximum independence. She noted that the Carers (Equal Opportunities) Act 2004 had not been implemented as intended in every area. Supporting family carers well would in turn ensure that their relatives could lead valued and fulfilling lives.

16. She told the Committee that inadequate data is held on people with learning disabilities and family carers. There is not enough detail about local need and so services have developed in an ad hoc way. Alison Giraud-Saunders stressed that there are "pockets" of good practice in data gathering and strategic planning. Sheffield is one example of such good practice, with a longstanding and robust register of people with learning disabilities. They have excellent data and make good use of it, for example in planning for the

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<sup>480</sup> The DRC define Independent Living as follows: '*Independent living means ensuring that disabled people of all ages have the same freedom, choice, dignity and control as other citizens at home, work, and in the community. It does not mean living by yourself or fending for yourself. It means the right to the practical assistance and any necessary support in order to participate fully in society and to live an ordinary life.*'

transition of young people with complex needs, or for ageing family carers. They are very unusual. However, they probably still do not know of everyone who may have a learning disability in Sheffield.

### *Independent living and people with complex support needs*

17. When asked about independent living and people with complex support needs, Richard Jackson told the Committee about his concern that some people with learning disabilities are without capacity from birth. In these circumstances, the role of families is very important. Little is said about family advocates. However, RESCARE believe that families are the natural decision makers on the behalf of people with learning disabilities.

18. Richard Jackson expressed his concern that independence is not the prerogative of supported living. He told the Committee that there are some people with learning disabilities who are not going to be independent. RESCARE believes primarily in the right to choose. People with learning disabilities and their parents should have choice between a variety of service options. RESCARE are seriously concerned about the declining service with the closure of special day and residential schools, day centres and the recent movement campaigning against all residential care provision. They consider that thousands of people with severe learning disabilities and their families are being marginalized and sidelined as a 'crisis led' rather than a 'needs led' service develops.

19. Both Viv Cooper and Philippa Russell told the Committee that their sons, both of whom had complex needs were living in homes in the community, although it had taken an enormous amount of work to make this happen. Viv Cooper told the Committee that her son has learning disabilities, including challenging behaviour and has high support needs. She does not believe that her son is unable to live independently. She stressed that families can co-ordinate, organise, support and manage packages of care. Although families need help and support to do this, it is possible for people with complex needs to live within the community. Although it is possible, it is not typical and the systems are stacked against making it happen. Philippa Russell emphasised that 'independent living' did not mean living in the community without appropriate support.

### *Housing*

20. The Committee asked about the barriers faced by people with learning disabilities who were trying to access housing for supported living. Alison Giraud-Saunders thought that there were three problems: (i) a shortage of suitable housing; (ii) a lack of prioritisation of people with learning disabilities within the system; and (iii) a lack of creative commissioning. She told the Committee that people with learning disabilities are at the bottom of the queue for social housing provision. There are not enough new houses being built allowing people to live with support. An individual with a learning disability who needs support at home may well need a bigger place to live than an individual without a learning disability, such as a two bedroom place rather than one bedroom to accommodate overnight support and allow space for bulky equipment. There is a great shortage of suitable housing. She had heard from families told to evict their son/daughter so that they become eligible for housing assistance. There is currently a lack of creativity in housing provision. For example, in one case, where necessary adaptations could not be made to a family's home to allow their relative with learning disabilities to live there, the PCT sent the

person to distant residential accommodation, rather than move the family to a house that could be adapted. The adaptations would have been cheaper than sending the person to residential care.

### ***Funding, eligibility and access to services***

21. In response to a number of questions about funding, eligibility and access to services, the following points were made in discussion.

22. Philippa Russell told the Committee that having people live in homes in their local communities rather than in specialist out of county residential care could represent a major saving for the local authority. However, she considered that local authorities and PCTs must ensure that there is a strong infrastructure of services to support a successful move towards independent living. Placement breakdowns and crisis intervention are expensive and in many cases could have been avoided.

23. Richard Jackson told the Committee that there is enough money in the system but raised his concerns that it is not reaching the front line of care as intended, and is not ring fenced. For example, money from selling off former hospital sites for people with learning disabilities has not gone back into the service for people with learning disabilities although this was promised. He told the Committee that people with learning disabilities are at the bottom of the Government's funding priorities. RESCARE considers that supported living conveniently moves the burden of caring for people with learning disabilities from local authority budgets to the benefits system and the budget of central Government.

24. The other witnesses expressed their disagreement with this view. Alison Giraud-Saunders told the Committee that currently there was inadequate funding to meet demographic changes (including increased life expectancy) and increasing demand for services.

25. When asked by Committee members to explain how the current system could be improved without further funding, Viv Cooper told the Committee that the answer lay in the proper management of transition from childhood to adult services, individual budgets and direct payments. It was a real problem within the current arrangements that funding streams couldn't or wouldn't mix. She considered that the system needed to be made simpler in order to maximise current levels of funding and that there needs to be someone responsible for co-ordinating services on behalf of any person with learning disabilities. Philippa Russell added that where a person had access to individual budgets there should be an element of funding within their individual budget allocation for someone to coordinate it. However, people need advice and information and training about what the options are. Currently, too many disabled people and family carers lack the information, advice, training and support necessary in order to understand all possible options and to make informed choices.

26. Alison Giraud-Saunders told the Committee that there are already some good examples of bringing together funding streams well. In order to improve services within current funding limitations, she said local Authorities need good information on people with learning disabilities within their areas of responsibility so that planning can start early. People need to start thinking from early in a child's life.

27. There needs to be more creative thinking and a change in attitudes. Specifically, there is not always as much creative thinking in mainstream services, which people with learning disabilities use, as there is in the better services which are particularly for people with learning disabilities.

### **Carers**

28. When asked about people with learning disabilities acting as carers for others, Alison Giraud-Saunders told the Committee that more often, as the population ages and people with learning disabilities continue to live for longer, people with learning disabilities are undertaking a primary caring role. However, they are not being recognised as carers and often don't get a carers assessment. There was insufficient data available to give interested parties an accurate view of the breadth of this problem.

### **Concluding statements**

29. Philippa Russell told the Committee that there needed to be a wider debate and shared understanding about what we mean by 'human rights'. The concept of 'human rights' should be associated with high expectations of public services and of society as a whole. The shortfall in advocacy services means that many people with learning disabilities lack the support they need in order to make best use not only of human rights legislation but also of disability discrimination and other legislation which might enable them to access services and get a better quality of life. Family carers have human rights too, but sadly understanding and ability to use the human rights legislation to best effect are still limited.

30. Richard Jackson told the Committee that people with learning disabilities need life long care, support and protection to a varying degree according to the extent of their disabilities. It is not a case of one type of provision versus another but a comprehensive service with each having a part to play. There should not be a battle but a united front seeking the implementation of *Valuing People* in full with its choice of options. He told the Committee that parents and relatives are concerned that we are witnessing, and in danger of allowing, an abdication by the State of any meaningful care of those who cannot care for themselves and that this could only be against their human rights.

## **Panel 2: Access to justice**

Kathryn Stone, Chief Executive, VOICE UK.

Robin Van Den Hende, Policy and Campaigns Officer, Respond/VOICE UK/Ann Craft Trust.

Jenny Talbot, Programme Manager, Prison Reform Trust.

### **Human rights and crimes against people with learning disabilities**

31. The Committee asked whether the introduction of the HRA had made any difference to the way that people with learning disabilities were treated by the criminal justice system

and whether “taking a human rights based approach” to the provision of public services could help reform negative attitudes. The following points were made in discussion.

32. Robin Van Den Hende told the Committee that the HRA had led to no significant change in the attitudes of the general public towards people with learning disabilities. However, people with learning disabilities have started talking more about human rights and asking for their human rights to be respected. He thought that the HRA has had some effect on professionals in that discussions relating to people’s welfare increasingly use both the language of human rights and a human rights framework. He added that good practice aims to, and does, ensure respect for human rights, even if the language of good practice is not the language of human rights.

33. Kathryn Stone thought that the low number of prosecutions for crime against people with learning disabilities raised an interesting and important point. People with learning disabilities are seen to be different and they are treated differently by the media if they are murdered. People know the name of Victoria Climbié, but not the names of vulnerable people with learning disabilities who have been recently killed. The abuse of people with learning disabilities is a crime and needs to be treated as a crime, not just called abuse and dealt with as a disciplinary issue. The point is that if people with learning disabilities are seen as having human rights, they will be seen as being the same as other people.

### ***Bullying, Harassment and Hate Crime***

34. Committee members invited the witnesses to expand on how people with learning disabilities are treated by the criminal justice system and by the police. The following points were made:

35. Robin Van Den Hende told the Committee that “abuse” of adults with learning disabilities is not generally treated as a crime, even when that abuse does involve a breach of the criminal law (e.g. assault, sexual assault or fraud). The police are often called late in the process when evidence has degraded and it has become difficult to take statements from witnesses. Recently produced figures on adult protection referrals to Cornwall Adult Protection Committee illustrate this. Between October 2006 and March 2007 62% of adult protection referrals to the Cornwall Adult Protection Committee were either substantiated or partly substantiated. However, the Police were only involved in 9% of those investigations. Only 1% of these allegations led to a prosecution. Part of the problem is that people do not see adults with learning disabilities as people with equal rights to protection by the law.

36. Kathryn Stone told the Committee that research shows that police can fail to identify that a person has learning disabilities and they are reluctant to accept that a crime has been committed because a person has a learning disability. There is some good work being done by police forces to raise awareness about how to identify people with learning disabilities, and support them in giving evidence, including the introduction of the intermediary scheme under the Youth Justice and Criminal Evidence Act. Robin Van Den Hende told the Committee that the answer to the problem is in training in learning disabilities which is uniform across the country. He showed the Committee a copy of the Police Vulnerable Witness Pocket Guide, a credit card sized, fold-out guide for police officers on how to identify and help people with learning disabilities who had experienced crime. The Pocket

Guide was produced by VOICE UK, Respond and the Ann Craft Trust in conjunction with the Association of Chief Police Officers and has been distributed to every front line police officer in England and Wales.

37. Kathryn Stone told the Committee that VOICE UK have been campaigning for a long time for people to have equal access to the criminal justice system. This should be put in the context of the development of good practice. The treatment of people with learning disabilities could be compared with the treatment of children in the criminal justice system who are witnesses. While the need to assist children in giving evidence is widely recognised and acted upon, there is not the same recognition that people with learning disabilities can give good evidence providing they receive appropriate assistance. We need to think how to treat people in the criminal justice system if they are “different” and need different treatment to access justice.

38. The report *Behind Closed Doors* shows that people with learning disabilities sometimes do not know that what is being done to them is a criminal act. Instead, many people with learning disabilities believe that the crime that they suffer is simply a normal part of life. Even if people recognise that a crime has taken place, it can be difficult for people with learning disabilities to communicate their concerns if they have a communication difficulty. It is also difficult if the complaint is about the person providing care as a person with learning disabilities may fear the loss of care, accommodation or other support if they make a complaint and/or make a report to the police. Once a complaint has been made, the CPS may think that the complainant with learning disabilities won't be able to give evidence, or that it will be too stressful for them to do so and this may reduce the likelihood of a successful prosecution.

39. Since the publication of *Behind Closed Doors*, a number of publications have been produced and there are drives by grassroots advocacy organisations to improve the situation. Their effectiveness is demonstrated by the Sutton and Merton inquiry.

## **Training**

40. Committee members asked whether training needed to be provided to the police and others working within the criminal justice system. The following points were made.

41. Robin Van Den Hende added that the principle reasons why people with learning disabilities were more likely to be victims of crime and abuse are (i) the failure of the public to understand and empathise with people with learning disabilities and (ii) the vulnerability of people with learning disabilities. This vulnerability comes about because crime against this group are seen as being easier to commit and to get away with. This, in turn, is because (a) people with learning disabilities may have different communication needs that may not always be recognised by those to whom they could report crime and (b) the fact that some people with learning disabilities maybe too trusting of other people. The police need training and increased awareness if they are to help people with learning disabilities who have been the victims of crime. Police want to help vulnerable individuals, but some officers simply do not understand learning disabilities and the help that is available to let people with learning disabilities give their best evidence. Kathryn Stone added that any training scheme should be rolled out across the country.

42. Committee members asked whether training also needed to be provided to people with learning disabilities. Robin Van Den Hende stated that it should. He explained that change and training was needed on many levels as there are multiple hurdles that a victim with learning disabilities has to overcome to get justice. Many adults with learning disabilities won't recognise that even serious offences are a crime. They may be too scared and intimidated to report it, especially if the crime has been committed by someone working in their home or service. They may not know how to report it. Education for people with learning disabilities would address this. However, even if they report a crime, a care provider may not take the issue any further. Social care professionals may want to sweep it under the carpet and not go to the police. They may investigate the matter themselves instead of involving the police. Even if the crime is reported to the police, the police do not always consider providing special measures and may think the individual with a learning disability can't give evidence. At prosecution level, the CPS may decide not to pursue a prosecution as they consider that the victim cannot give evidence or that it would be too distressing for them to do so.

43. Training is not currently available across the board or at national level. Police officers may only receive a couple of hours of training on disability during their basic training. Training should be given to police officers on identifying people with learning disabilities so that they can be identified at an early stage in the criminal justice process. The police need to realise what having a learning disability means and how they can meet the needs of people with learning disabilities. The police also need to be aware of the special measures currently available to them.

### ***People with learning disabilities as accused***

44. The Committee asked about the problems facing people with learning disabilities accused of crimes. Jenny Talbot stressed the similarities with the difficulties faced by victims. She considered that there needed to be an increased focus on training and awareness. In particular, police officers in custody suites should undertake awareness training to assist in the identification of people with learning disabilities. In addition there needs to be a systematic screen to identify those people who might have learning disabilities. However, it is important to recognise that people often have developed coping mechanisms to hide their learning disabilities which makes it harder for police to identify this group of people. Offending behaviour is not always reported if people live in care homes. The Police may only be called when offending behaviour has got out of control when people with learning disabilities might have benefited from earlier intervention by the police, for example by being cautioned.

45. The Prison Reform Trust consider that the criminal justice system should provide support mechanisms for both suspects and defendants with learning disabilities. A failure to provide this support leads to a significantly increased risk of an unfair trial and miscarriage of justice for defendants with learning disabilities.

46. The Committee asked if the difficulties faced by people with learning disabilities were commensurate with the problems faced by those with mental health problems. Jenny Talbot told the Committee that, if we lifted all people with mental health problems out of prison, there would not be an overcrowding problem and that this would ease the pressure on the system. However, not all people with learning disabilities have mental health

problems, although some do. There is also the question as to whether prison is the most appropriate place for helping people with learning disabilities to stop offending.

47. By far the biggest group of people with learning disabilities in prison are those with mild learning disabilities, many of whom are unlikely to 'qualify' for support from community learning disability teams and/or local authority social services departments. People with learning disabilities are likely to need additional support to help them to understand what is happening to them at various points within the criminal justice system. The Prison Reform Trust considers that there needs to be more trained "appropriate adults" working in the criminal justice system to support this group of people.

48. On a practical level, the Prison Reform Trust considers that the following changes are necessary:

- Police should consistently be able to identify suspects who might have a learning disability and should be able to make an appropriate referral for assessment;
- People with suspected learning disabilities should not be interviewed without an appropriate adult;
- Appropriate adults should be accessible 24 hours a day, seven days a week; they should be statutorily funded and appropriately trained
- The appropriate adult scheme should be extended into attendance at court with the suspect/defendant ;
- There needs to be reform of the court process to assist people with learning disabilities (and others) to both understand and to participate in their own trial. For example, allowing for court visits pre-trial and providing accessible information at court. These reforms need to be part of a systematic national programme of change.
- Greater opportunities for community orders for people with learning disabilities should be explored and provided.
- Significantly improved data sharing between the different departments of the criminal justice system so that once a suspect has been identified as having learning disabilities the appropriate support can be put into place throughout the criminal justice process.
- Prison regimes should be made fully accessible to the whole prison population. In particular there should be full access to information, offending behaviour programmes and opportunities for education, training and employment

49. The Committee asked why there appeared to be breaches of PACE in the anecdotal evidence provided by the Prison Reform Trust in their written submissions. Jenny Talbot told the Committee that the possibilities included a lack of training, poor policing, busy custody suites, lack of time and pressure to process people quickly. Another reason might be that if the police identify someone as needing support, they would take more time and resources to deal with them, so it might be easier not to identify them.

50. When asked whether prosecution lawyers have training on how to modify their behaviour when dealing with people with learning disabilities, Kathryn Stone told the Committee that it is the role of the lawyer to challenge evidence. However, she advocated the use of intermediaries for defendants as well. Lawyers and judges need additional skills and training. There are examples of where people have not been asked the right questions in court e.g. when asked “do you follow?”, a person with learning disabilities might think that they have to physically follow someone somewhere. They will understand “do you understand?”. Similarly a person did not understand a whole series of questions that they were asked about the weather (Was it cloudy/sunny/rainy etc?), but did understand when they were asked “what was the weather like?”. Language can be moderated and it does not cost anything. There was a risk of unfair trial if someone could not understand what was going on. She considered that there should be an extended use of intermediaries along the lines currently being piloted in some places.

51. Kathryn Stone confirmed that VOICE UK were involved with the Judicial Studies Board on raising awareness of learning disability among judges.

### ***Prisoners with a learning disability***

52. Jenny Talbot told the Committee that, to be considered for parole, prisoners need to demonstrate that they understand their crime and show remorse and are often required to have participated in relevant offending behaviour (cognitive skills) programmes. People with learning disabilities may be excluded from participating in such programmes and may spend longer in prison as a result. This is because offending behaviour programmes tend only to be for people with an IQ of over 80 and with a certain degree of literacy. Cognitive skills programmes are often not accessible for people with learning disabilities. There is also a problem with accessing support services in prison, for example it is not clear what support should be made available from PCTs and social services. She told the Committee there is a problem of ‘silos of information’ in prisons, for example information isn’t shared between departments, often to the extent that prison staff do not know what support is available at their prison for this group of prisoners if it is provided by another department within the prison. She considered that, in some of the new contracts between PCTS/prisons/social services, the rules on sharing of information are not clear; staff sometimes hide behind patient confidentiality because they are unsure about what information they may share and what they may not.

53. Jenny Talbot told the Committee that, in her opinion, there were potentially more miscarriages of justice for people with learning disabilities than for those without.

# Formal Minutes

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Tuesday 22 January 2008

Members present:

Mr Andrew Dismore MP, in the Chair

Lord Dubs

Dr Evan Harris MP

Lord Morris of Handsworth

Baroness Stern

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Draft Report [A Life Like Any Other? Human Rights of Adults with Learning Disabilities], proposed by the Chairman, brought up and read.

*Ordered*, That the draft Report be read a second time, paragraph by paragraph.

Paragraphs 1 to 303 read and agreed to.

Annexes read and agreed to.

Summaries read and agreed to.

Several Papers were ordered to be appended to the Report.

*Resolved*, That the Report be the Seventh Report of the Committee to each House.

*Ordered*, That the Chairman make the Report to the House of Commons and that Baroness Stern make the Report to the House of Lords.

*Ordered*, That embargoed copies of the Report be made available, in accordance with the provisions of Standing Order No. 134.

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[Adjourned till Monday 28 January 2008 at 4pm.]

## List of Witnesses

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|                                                                                                                                                                                                                                                                                                                                                              | <i>Page</i>  |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------|
| <b>Monday 25 June 2007</b>                                                                                                                                                                                                                                                                                                                                   |              |
| <b>Dame Jo Williams</b> , Chief Executive, MENCAP, and <b>Mr Andrew Lee</b> , Director, People First (Self-Advocacy).                                                                                                                                                                                                                                        | <b>Ev 1</b>  |
| <b>Ms Eve Rank</b> , Commissioner, and <b>Mr Mark Shrimpton</b> , Assistant Director, Legal and Operations, Disability Rights Commission.                                                                                                                                                                                                                    | <b>Ev 6</b>  |
| <b>Monday 9 July 2007</b>                                                                                                                                                                                                                                                                                                                                    |              |
| <b>Ms Sonya Sceats</b> , Policy and Research Officer, British Institute of Human Rights;<br><b>Ms Anne Lofthouse</b> , Lead Officer for Service User and Carer Involvement in Learning Disabilities; <b>Ms Lindsey Dyer</b> , Director, Service Users and Carers, Mersey Care NHS Trust; and <b>Ms Joanna Perry</b> , Board of Trustees, Values Into Action. | <b>Ev 9</b>  |
| <b>Ms Ruth Scott</b> , Head of Policy and Government Affairs, Scope; <b>Professor Tony Holland</b> , Health Foundation Chair in Learning Disabilities, Department of Psychiatry and<br><b>Ms Amy Forgacs</b> , Cambridge Centre for Participation; <b>Ms Philipa Bragman</b> , Director, and <b>Mr Shaun Webster</b> , Project Co-Ordinator.                 | <b>Ev 15</b> |
| <b>Monday 22 October 2007</b>                                                                                                                                                                                                                                                                                                                                |              |
| <b>Mr Rob Greig</b> , National Co-Director for Learning Disabilities and Co-Chair of the National Task Force for Learning Disability.                                                                                                                                                                                                                        | <b>Ev 22</b> |
| <b>Monday 12 November 2007</b>                                                                                                                                                                                                                                                                                                                               |              |
| <b>Mr Ivan Lewis</b> , a Member of the House of Commons, Minister for Care Services, Department of Health, and <b>Mrs Anne McGuire</b> , a Member of the House of Commons, Minister for Disabled People, Department for Work and Pensions.                                                                                                                   | <b>Ev 31</b> |

## List of Written Evidence

---

|                                                                                                  | <i>Page</i> |
|--------------------------------------------------------------------------------------------------|-------------|
| 1 Memorandum from Trust, Caring & Nursing Agency                                                 | Ev 48       |
| 2 Memorandum from Find a Voice                                                                   | Ev 48       |
| 3 Memorandum from Winchester and District Mencap Society                                         | Ev 49       |
| 4 Letter from the Sunlight Development Trust                                                     | Ev 50       |
| 5 Memorandum from the Compass Advocacy Network                                                   | Ev 51       |
| 6 Letter from Sussex Partnership NHS Trust, Community Team for People with a Learning Disability | Ev 52       |
| 7 Memorandum from the Brandon Trust                                                              | Ev 52       |
| 8 Memorandum from RESCARE                                                                        | Ev 55       |
| 9 Supplementary memorandum from Rescare                                                          | Ev 56       |
| 10 Memorandum by Diane Ferguson, Advocacy Project Worker, Hambleton & Richmondshire Advocacy     | Ev 56       |
| 11 Memorandum by Choice for All Doncaster                                                        | Ev 58       |
| 12 Memorandum by Supporting Asperger Families in Essex (SAFE)                                    | Ev 59       |
| 13 Memorandum by Ann Abraham, Parliamentary and Health Service Ombudsman                         | Ev 62       |
| 14 Memorandum by Denise Redman, Scheme Manager, Royal Mencap Society                             | Ev 63       |
| 15 Memorandum by Somerset Advocacy                                                               | Ev 65       |
| 16 Memorandum by Speakeasy Now                                                                   | Ev 67       |
| 17 Memorandum by The Wednesday Comet Group                                                       | Ev 69       |
| 18 Memorandum by the Cambridgeshire Parliament                                                   | Ev 69       |
| 19 Memorandum from the Cheshire and Wirral Partnership Trust Learning Disabilities Division      | Ev 72       |
| 20 Memorandum from Scope                                                                         | Ev 78       |
| 21 Memorandum from The Judith Trust                                                              | Ev 88       |
| 22 Memorandum from Disability Action                                                             | Ev 89       |
| 23 Letter from St Anne's Community Services                                                      | Ev 95       |
| 24 Memorandum from the Department of Health                                                      | Ev 96       |
| 25 Supplementary Memorandum from the Department of Health                                        | Ev 103      |
| 26 Memorandum from Midstream (West Lancs) Ltd                                                    | Ev 104      |
| 27 Letter from Speaking Up                                                                       | Ev 107      |
| 28 Memorandum by Jan Thurlow                                                                     | Ev 110      |
| 29 Memorandum from Edwin Leach                                                                   | Ev 112      |
| 30 Memorandum from Alan Leyin, Chartered Clinical Psychologist                                   | Ev 113      |
| 31 Memorandum from the Centre for Participation (C4P), Cambridge                                 | Ev 116      |
| 32 Memorandum from Inclusion North Steering Group                                                | Ev 118      |
| 33 Memorandum from Pembrokeshire Advocacy                                                        | Ev 120      |
| 34 Memorandum from The KingFisher Resource Centre, Peterborough                                  | Ev 122      |
| 35 Memorandum from the Royal College of General Practitioners                                    | Ev 123      |
| 36 Memorandum from the Independent Advocacy Services                                             | Ev 125      |
| 37 Memorandum by Colchester Mencap                                                               | Ev 126      |

|    |                                                                                                    |        |
|----|----------------------------------------------------------------------------------------------------|--------|
| 38 | Memorandum from Citizenship Opportunities and Safety Training (COAST)                              | Ev 129 |
| 39 | Memorandum from the British Institute of Human Rights                                              | Ev 131 |
| 40 | Memorandum by NHS Lothian, Scotland                                                                | Ev 133 |
| 41 | Memorandum from Mencap                                                                             | Ev 135 |
| 42 | Letter from the NHS Confederation                                                                  | Ev 151 |
| 43 | Memorandum by Change                                                                               | Ev 151 |
| 44 | Memorandum from Walsall Council                                                                    | Ev 154 |
| 45 | Memorandum from The British Psychological Society                                                  | Ev 160 |
| 46 | Memorandum from the Swansea Participation Service                                                  | Ev 163 |
| 47 | Memorandum from Capability Scotland                                                                | Ev 165 |
| 48 | Memorandum from Prison Reform Trust                                                                | Ev 166 |
| 49 | Memorandum from Anne McGuire MP, Minister for Disabled People,<br>Department for Work and Pensions | Ev 177 |
| 50 | Memorandum from Mersey Care NHS Trust                                                              | Ev 177 |
| 51 | Memorandum by the Healthcare Commission                                                            | Ev 179 |
| 52 | Memorandum from Alan F Snow                                                                        | Ev 183 |
| 53 | Memorandum from the Shields Parliament                                                             | Ev 184 |
| 54 | Memorandum from Our Choice Project                                                                 | Ev 184 |
| 55 | Memorandum by Inclusion International                                                              | Ev 185 |
| 56 | Memorandum from The Royal College of Psychiatrists                                                 | Ev 191 |
| 57 | Memorandum from the Princes Royal Trust                                                            | Ev 194 |
| 58 | Memorandum by the Disability Rights Commission                                                     | Ev 196 |
| 59 | Memorandum on behalf of the PMLD Network by<br>Beverley Dawkins (Mencap)                           | Ev 202 |
| 60 | Letter from National Group of Speech and Language Therapists                                       | Ev 210 |
| 61 | Memorandum from the Foundation for People with Learning Disabilities                               | Ev 211 |
| 62 | Memorandum from the Norah Fry Research Centre, University of Bristol                               | Ev 222 |
| 63 | Memorandum from the Down's Syndrome Association                                                    | Ev 225 |
| 64 | Memorandum from the South East Regional Family Carer Network                                       | Ev 231 |
| 65 | Memorandum from Values into Action                                                                 | Ev 232 |
| 66 | Memorandum by the British Humanist Association                                                     | Ev 240 |
| 67 | Memorandum from the Challenging Behaviour Foundation                                               | Ev 242 |
| 68 | Memorandum from Voice UK, Ann Craft Trust and Respond                                              | Ev 246 |
| 69 | Supplementary memorandum from Voice UK, Ann Craft Trust and Respond                                | Ev 279 |
| 70 | Further supplementary memorandum from Voice UK, Ann Craft<br>Trust and Respond                     | Ev 281 |
| 71 | Further supplementary memorandum from Voice UK, Ann Craft<br>Trust and Respond                     | Ev 286 |
| 72 | Memorandum from the National Family Carers Network                                                 | Ev 287 |
| 73 | Memorandum by the Scottish Consortium for Learning Disability                                      | Ev 298 |
| 74 | Memorandum from the Department for Innovation, Universities and Skills                             | Ev 299 |
| 75 | Memorandum from the Human Rights Department of<br>Leigh Day & Co Solicitors                        | Ev 304 |
| 76 | Memorandum from the National Institute of Adult Continuing<br>Education (NIACE)                    | Ev 310 |
| 77 | Memorandum from the Working Together with Parents Network                                          | Ev 313 |

|     |                                                                                                                |        |
|-----|----------------------------------------------------------------------------------------------------------------|--------|
| 78  | Memorandum from Who cares for us?                                                                              | Ev 317 |
| 79  | Memorandum from the Commission for Social Care Inspection                                                      | Ev 318 |
| 80  | Memorandum by Mencap in Northern Ireland                                                                       | Ev 322 |
| 81  | Memorandum from People First Scotland                                                                          | Ev 327 |
| 82  | Memorandum by in Control                                                                                       | Ev 329 |
| 83  | Memorandum from Skill: National Bureau for Students with Disabilities                                          | Ev 331 |
| 84  | Memorandum from Learning Disability Wales                                                                      | Ev 334 |
| 85  | Memorandum from the Learning Disability Alliance Scotland                                                      | Ev 335 |
| 86  | Memorandum from Advocacy Partners                                                                              | Ev 337 |
| 87  | Memorandum from the British Institute of Learning Disabilities (BILD)                                          | Ev 343 |
| 88  | Memorandum from The Home Farm Trust                                                                            | Ev 352 |
| 89  | Memorandum from the Family Welfare Association (FWA)                                                           | Ev 353 |
| 90  | Memorandum from Rotherham Advocacy Partnerships                                                                | Ev 357 |
| 91  | Memorandum from the Wokingham Learning Disability Partnership Board                                            | Ev 358 |
| 92  | Memorandum from The National Autistic Society                                                                  | Ev 360 |
| 93  | Memorandum from The Royal College of Speech and Language Therapists                                            | Ev 363 |
| 94  | Memorandum from SeeAbility                                                                                     | Ev 373 |
| 95  | Memorandum from United Response                                                                                | Ev 377 |
| 96  | Memorandum by Speaking Up For Yourself In Brent                                                                | Ev 381 |
| 97  | Letter from the Chairman to Michael Wills MP, Human Rights Minister,<br>Ministry of Justice                    | Ev 384 |
| 98  | Letter from the Chairman to the Rt Hon Jacqui Smith MP, Home Secretary                                         | Ev 384 |
| 99  | Letter from the Chairman to Anne McGuire MP, Minister for Disabled People,<br>Department for Work and Pensions | Ev 385 |
| 100 | Letter from Anne McGuire MP, Minister for Disabled People,<br>Department for Work and Pensions                 | Ev 386 |
| 101 | Memorandum from Anne McGuire MP, Minister for Disabled People,<br>Department for Work and Pensions             | Ev 387 |
| 102 | Memorandum from KeyRing                                                                                        | Ev 390 |
| 103 | Supplementary Memorandum from KeyRing                                                                          | Ev 391 |
| 104 | Memorandum by the Crown Prosecution Service                                                                    | Ev 392 |
| 105 | Memorandum by the Association of Chief Police Officers of England,<br>Wales and Northern Ireland               | Ev 402 |
| 106 | Letter from Ann McGuire MP, Minister for Disabled People,<br>Department for Work and Pensions                  | Ev 403 |
| 107 | Letter from Michael Wills MP, Minister of State, Ministry of Justice                                           | Ev 405 |
| 108 | Letter from Ivan Lewis MP, Parliamentary Under Secretary of State,<br>Department of Health                     | Ev 405 |
| 109 | Letter from Roger Hill, Director of Probation, Ministry of Justice                                             | Ev 405 |
| 110 | Letter from the Chair to Mr Phil Wheatley, Director General of HM Prison<br>Service, HM Prison Service         | Ev 406 |
| 111 | Memorandum from Mr John Pearson                                                                                | Ev 407 |
| 112 | Memorandum from Ms Veronica Dunn                                                                               | Ev 408 |
| 113 | Memorandum by Joanne Hickinbotham and Steven Parkes                                                            | Ev 410 |
| 114 | Memorandum by Simon Cramp                                                                                      | Ev 411 |
| 115 | Memorandum by Miss Heather Crozier, Community Learning Disability Nurse                                        | Ev 413 |

NOTE:

The Report of the Committee is published in Volume I, HL Paper 40-I, HC 71-I.

The Evidence of the Committee is published in Volume II, HL Paper 40-II, HC 71-II.

Evidence received by the Committee but not printed can be inspected at the Parliamentary Archives, email: [archives@parliament.uk](mailto:archives@parliament.uk)

# Reports from the Joint Committee on Human Rights in this Parliament

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## The following reports have been produced

### Session 2007-08

|                |                                                                                                                             |                         |
|----------------|-----------------------------------------------------------------------------------------------------------------------------|-------------------------|
| First Report   | Government Response to the Committee's Eighteenth Report of Session 2006-07: The Human Rights of Older People in Healthcare | HL Paper 5/HC 72        |
| Second Report  | Counter-Terrorism Policy and Human Rights: 42 days                                                                          | HL Paper 23/HC 156      |
| Third Report   | Legislative Scrutiny: 1) Child Maintenance and Other Payments Bill; 2) Other Bills                                          | HL Paper 28/ HC 198     |
| Fourth Report  | Government Response to the Committee's Twenty-First Report of Session 2006-07: Human Trafficking: Update                    | HL Paper 31/ HC 220     |
| Fifth Report   | Legislative Scrutiny: Criminal Justice and Immigration Bill                                                                 | HL Paper 37/HC 269      |
| Sixth Report   | The Work of the Committee in 2007 and the State of Human Rights in the UK                                                   | HL Paper 38/HC 270      |
| Seventh Report | A Life Like Any Other? Human Rights of Adults with Learning Disabilities: Volume I Report and Formal Minutes                | HL Paper 40-I/HC 73-I   |
| Seventh Report | A Life Like Any Other? Human Rights of Adults with Learning Disabilities: Volume II Oral and Written Evidence               | HL Paper 40-II/HC 73-II |

### Session 2006-07

|                 |                                                                                   |                         |
|-----------------|-----------------------------------------------------------------------------------|-------------------------|
| First Report    | The Council of Europe Convention on the Prevention of Terrorism                   | HL Paper 26/HC 247      |
| Second Report   | Legislative Scrutiny: First Progress Report                                       | HL Paper 34/HC 263      |
| Third Report    | Legislative Scrutiny: Second Progress Report                                      | HL Paper 39/HC 287      |
| Fourth Report   | Legislative Scrutiny: Mental Health Bill                                          | HL Paper 40/HC 288      |
| Fifth Report    | Legislative Scrutiny: Third Progress Report                                       | HL Paper 46/HC 303      |
| Sixth Report    | Legislative Scrutiny: Sexual Orientation Regulations                              | HL Paper 58/HC 350      |
| Seventh Report  | Deaths in Custody: Further Developments                                           | HL Paper 59/HC 364      |
| Eighth Report   | Counter-Terrorism Policy and Human Rights: Draft Prevention of Terrorism Act 2005 | HL Paper 60/HC 365      |
| Ninth Report    | The Meaning of Public Authority Under the Human Rights Act                        | HL Paper 77/HC 410      |
| Tenth Report    | The Treatment of Asylum Seekers: Volume I Report and Formal Minutes               | HL Paper 81-I/HC 60-I   |
| Tenth Report    | The Treatment of Asylum Seekers: Volume II Oral and Written Evidence              | HL Paper 81-II/HC 60-II |
| Eleventh Report | Legislative Scrutiny: Fourth Progress Report                                      | HL Paper 83/HC 424      |

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|---------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------|
| Twelfth Report      | Legislative Scrutiny: Fifth Progress Report                                                                                                                                                                  | HL Paper 91/HC 490        |
| Thirteenth Report   | Legislative Scrutiny: Sixth Progress Report                                                                                                                                                                  | HL Paper 105/HC 538       |
| Fourteenth Report   | Government Response to the Committee's Eighth Report of this Session: Counter-Terrorism Policy and Human Rights: Draft Prevention of Terrorism Act 2005 (Continuance in force of sections 1 to 9 order 2007) | HL Paper 106/HC 539       |
| Fifteenth Report    | Legislative Scrutiny: Seventh Progress Report                                                                                                                                                                | HL Paper 112/HC 555       |
| Sixteenth Report    | Monitoring the Government's Response to Court Judgments Finding Breaches of Human Rights                                                                                                                     | HL Paper 128/HC 728       |
| Seventeenth Report  | Government Response to the Committee's Tenth Report of this Session: The Treatment of Asylum Seekers                                                                                                         | HL Paper 134/HC 790       |
| Eighteenth Report   | The Human Rights of Older People in Healthcare: Volume I- Report and Formal Minutes                                                                                                                          | HL Paper 156-I/HC 378-I   |
| Eighteenth Report   | The Human Rights of Older People in Healthcare: Volume II- Oral and Written Evidence                                                                                                                         | HL Paper 156-II/HC 378-II |
| Nineteenth Report   | Counter-Terrorism Policy and Human Rights: 28 days, intercept and post-charge questioning                                                                                                                    | HL Paper 157/HC 394       |
| Twentieth Report    | Highly Skilled Migrants: Changes to the Immigration Rules                                                                                                                                                    | HL Paper 173/HC 993       |
| Twenty-first Report | Human Trafficking: Update                                                                                                                                                                                    | HL Paper 179/HC 1056      |

#### Session 2005–06

|                   |                                                                                                                                                    |                          |
|-------------------|----------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------|
| First Report      | Legislative Scrutiny: First Progress Report                                                                                                        | HL Paper 48/HC 560       |
| Second Report     | Deaths in Custody: Further Government Response to the Third Report from the Committee, Session 2004–05                                             | HL Paper 60/HC 651       |
| Third Report      | Counter-Terrorism Policy and Human Rights: Terrorism Bill and related matters Volume I Report and Formal Minutes                                   | HL Paper 75-I/HC 561-I   |
| Third Report      | Counter-Terrorism Policy and Human Rights: Terrorism Bill and related matters Volume II Oral and Written Evidence                                  | HL Paper 75-II/HC 561-II |
| Fourth Report     | Legislative Scrutiny: Equality Bill                                                                                                                | HL Paper 89/HC 766       |
| Fifth Report      | Legislative Scrutiny: Second Progress Report                                                                                                       | HL Paper 90/HC 767       |
| Sixth Report      | Legislative Scrutiny: Third Progress Report                                                                                                        | HL Paper 96/HC 787       |
| Seventh Report    | Legislative Scrutiny: Fourth Progress Report                                                                                                       | HL Paper 98/HC 829       |
| Eighth Report     | Government Responses to Reports from the Committee in the last Parliament                                                                          | HL Paper 104/HC 850      |
| Ninth Report      | Schools White Paper                                                                                                                                | HL Paper 113/HC 887      |
| Tenth Report      | Government Response to the Committee's Third Report of this Session: Counter-Terrorism Policy and Human Rights: Terrorism Bill and related matters | HL Paper 114/HC 888      |
| Eleventh Report   | Legislative Scrutiny: Fifth Progress Report                                                                                                        | HL Paper 115/HC 899      |
| Twelfth Report    | Counter-Terrorism Policy and Human Rights: Draft Prevention of Terrorism Act 2005 (Continuance in force of sections 1 to 9) Order 2006             | HL Paper 122/HC 915      |
| Thirteenth Report | Implementation of Strasbourg Judgments: First                                                                                                      | HL Paper 133/HC 954      |

|                       | Progress Report                                                                                                     |                             |
|-----------------------|---------------------------------------------------------------------------------------------------------------------|-----------------------------|
| Fourteenth Report     | Legislative Scrutiny: Sixth Progress Report                                                                         | HL Paper 134/HC 955         |
| Fifteenth Report      | Legislative Scrutiny: Seventh Progress Report                                                                       | HL Paper 144/HC 989         |
| Sixteenth Report      | Proposal for a Draft Marriage Act 1949 (Remedial) Order 2006                                                        | HL Paper 154/HC 1022        |
| Seventeenth Report    | Legislative Scrutiny: Eighth Progress Report                                                                        | HL Paper 164/HC 1062        |
| Eighteenth Report     | Legislative Scrutiny: Ninth Progress Report                                                                         | HL Paper 177/ HC 1098       |
| Nineteenth Report     | The UN Convention Against Torture (UNCAT) Volume I Report and Formal Minutes                                        | HL Paper 185-I/<br>HC 701-I |
| Twentieth Report      | Legislative Scrutiny: Tenth Progress Report                                                                         | HL Paper 186/HC 1138        |
| Twenty-first Report   | Legislative Scrutiny: Eleventh Progress Report                                                                      | HL Paper 201/HC 1216        |
| Twenty-second Report  | Legislative Scrutiny: Twelfth Progress Report                                                                       | HL Paper 233/HC 1547        |
| Twenty-third Report   | The Committee's Future Working Practices                                                                            | HL Paper 239/HC 1575        |
| Twenty-fourth Report  | Counter-Terrorism Policy and Human Rights: Prosecution and Pre-Charge Detention                                     | HL Paper 240/HC 1576        |
| Twenty-fifth Report   | Legislative Scrutiny: Thirteenth Progress Report                                                                    | HL Paper 241/HC 1577        |
| Twenty-sixth Report   | Human trafficking                                                                                                   | HL Paper 245-I/HC<br>1127-I |
| Twenty-seventh Report | Legislative Scrutiny: Corporate Manslaughter and Corporate Homicide Bill                                            | HL Paper 246/HC 1625        |
| Twenty-eighth Report  | Legislative Scrutiny: Fourteenth Progress Report                                                                    | HL Paper 247/HC 1626        |
| Twenty-ninth Report   | Draft Marriage Act 1949 (Remedial) Order 2006                                                                       | HL Paper 248/HC 1627        |
| Thirtieth Report      | Government Response to the Committee's Nineteenth Report of this Session: The UN Convention Against Torture (UNCAT) | HL Paper 276/HC 1714        |
| Thirty-first Report   | Legislative Scrutiny: Final Progress Report                                                                         | HL Paper 277/HC 1715        |
| Thirty-second Report  | The Human Rights Act: the DCA and Home Office Reviews                                                               | HL Paper 278/HC 1716        |