

Further Government Response to the Joint Committee on Human Rights Report:
A Life Like Any Other?
Human Rights of Adults with Learning Disabilities

Presented to Parliament by the Secretary of State for Health by Command of Her Majesty January 2009

Cm 7536 £5.50



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Further Government Response to the Joint Committee on Human Rights Report: A Life Like Any Other? Human Rights of Adults with Learning Disabilities

Introduction

The Joint Committee on Human Rights (the Joint Committee) published its report *A Life like Any Other? Human Rights of Adults with Learning Disabilities*¹ on 6 March 2008. The Government published its response to the conclusions and recommendations in that report on 6 May 2008.²

In its response the Government committed to provide the Joint Committee with a further response when responding to the *Valuing People Now* consultation.³

This report sets out the Government's further response to the Joint Committee taking account of feedback from the *Valuing People Now* Consultation.⁴ It is being published alongside *Valuing People Now: A new three year strategy for people with learning disabilities.⁵*

It also includes an update on issues and progress since the Government response was published in May, including:

- publication of the Single Equalities Bill;
- *Healthcare for All* the report of the Independent Inquiry into access to healthcare for people with learning disabilities, which was published in July 2008;⁶
- progress on the consultation on Safeguarding and "No Secrets";
- Further action on the issue of Hate Crime.

A Human Rights approach

Introduction

The Joint Committee's report highlighted the importance of a human rights based approach for people with learning disabilities. The new *Valuing People Now* strategy reflects this approach: it reaffirms human rights as one of the four key guiding principles which underpin the whole strategy.

JCHR recommendation

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)

Government response

The new *Valuing People Now* strategy sets out the cross-government programme of action to deliver progress for people with learning disabilities over the next three years. It highlights some of the key Public Service Agreements (PSAs) and indicators which have been agreed across Government to measure progress, in particular:

 $^{^1}HL\ Paper\ 40\text{-}1/HC73\text{-}1;\ http://www.publications.parliament.uk/pa/jt200708/jtselect/jtrights/40/40i.pdf$

 $^{{}^2}http://www.dh.gov.uk/en/Publications and statistics/Publications/PublicationsPolicyAnd Guidance/DH_084614$

³ Valuing People Now: From progress to tranformation. Department of Health (2007)

⁴Summary of responses to the consultation on Valuing People Now: From progress to tranformation. www.dh.gov.uk/en/consultations

⁵ Valuing People Now: a new three-year strategy for people with learning disabilities. Department of Health (2009)

⁶Healthcare for All: Report of the Independent Inquiry into Access to Healthcare for People into Learning Disabilities, Sir Jonathan Michael, Department of Health (2008)

- a new indicator to show the number of people with learning disabilities known to local authorities who are receiving a comprehensive health check at least annually;
- indicators to measure the proportion of people with learning disabilities known to social services in paid work and the accommodation status of people with learning disabilities;
- PSA15 will provide general information on people's experience of the extent to which they feel they have choice and control over the support they need.

The Department of Health (DH) is exploring options for establishing a Public Health Observatory on learning disability. In addition:

- joint strategic needs assessments, in compliance with the Disability Equality Duty (DED), will include accurate information about the lives of people with learning disabilities;
- local learning disability partnerships may set local objectives based on *Valuing People Now* and measure and report on them;
- consideration should be given to establishing targets in local area agreements based on the new social inclusion performance indicators.

The *Valuing People Now* Delivery Plan is being published alongside the strategy. We will publish a summary position statement setting out how the existing performance frameworks relate to provision of services for people with learning disabilities in spring 2009.

JCHR recommendation

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)

Government response

The Government agrees that a human rights approach is central to delivering the *Valuing People Now* strategy.

That is why the strategy includes a specific section on human rights; and threads a human rights based approach throughout.

The strategy includes specific action to promote a human rights based approach, including:

- Promoting human rights in healthcare through promoting good practice;
- Additional guidance to public authorities on the effective implementation of their duties under the Human Rights Act;
- Working across the relevant Government departments, public services, relevant workforce organisations and professional bodies to influence the way they approach the recruitment, training and development of their staff including on equality and human rights;

• Ensuring that the Hate Crime Strategy which includes disability hate crime addresses the specific issues for people with learning disabilities.

JCHR recommendation

9. We urge the Government to ensure that any amendment to existing positive equality duties should strengthen rather than undermine their effectiveness. (Paragraph 61)

Government response

The Government's response to its consultation on proposals for the Equality Bill, published on 21 July 2008, made clear its decision to introduce a new streamlined public sector duty to replace the race, disability and gender equality duties and to extend the new equality duty to age, sexual orientation and religion or belief and make it explicit that it covers gender reassignment.

The Government's intention is to strengthen, not undermine, the existing public sector duties.

JCHR recommendation

14. We recommend that the Department of Health revisit this issue [of how the Government can support adults with learning disabilities to form relationships] in the redrafted *Valuing People Now*, in light of the evidence we have received. (Paragraph 88)

Government response – Valuing People Now

Valuing People Now emphasises the importance of enabling people with learning disabilities to meet new people, build and sustain social networks and relationships – including sexual relationships – and to lead a fulfilling life with access to a diverse range of social and leisure activities. It recognises the importance of person-centred plans which address the whole range of people's interests, likes and dislikes; and the ongoing support that people will often need to establish and maintain relationships and social networks.

JCHR recommendation

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)

Government response

The *Valuing People Now* strategy recognises that people with learning disabilities want to lead ordinary lives and do the things that most people take for granted – get a job, study and build social networks. The Government has prioritised people with learning disabilities through the work of the Social Exclusion Task Force in driving delivery of the cross-government Socially Excluded Adults PSA (PSA 16). The PSA 16 delivery plan will set out a programme to increase the numbers of adults with learning disabilities known to councils in paid work over the next 3 years; and to increase the proportion in settled accommodation. A cross-government employment strategy will be published in early 2009 which will include a significant expansion of employment opportunities for people with learning disabilities

JCHR recommendation

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)

Government response

Valuing People Now is a cross-government strategy for people with learning disabilities which includes services such as access to housing, employment and transport as well as social and healthcare. Key Government Departments (Departments for Children, Schools and Families,(DCSF), Work and Pensions, Communities and Local Government, Innovation, Universities and Skills and the Home Office) have all demonstrated their commitment to delivering the strategy and are represented on the cross-Government Learning Disability Programme Board which is chaired by the Minister for Care Services and the Director General for Social Care, Local Government and Care Partnerships at DH.

The biggest challenge remains making sure delivery happens across England. The strategy sets out actions to strengthen the role of local Learning Disability Partnership Boards and regional work to support development of local capacity and capability through the Government Offices. *Valuing People Now* encapsulates a real determination to drive forward change on the ground. A comprehensive Delivery Plan is being published alongside *Valuing People Now*.

JCHR recommendation

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 Duty and the Human Rights Act. (Paragraph 105)

Government response

Valuing People Now has at its heart a vision that mainstream public services – health, housing, education, employment – should ensure that they are accessible to and provide appropriate support for people with learning disabilities.

On health issues in particular, the strategy sets out the Government's response to the ten main recommendations in *Healthcare for All*, the report of the Independent Inquiry into access to healthcare for people with learning disabilities.

A senior level Steering Group within DH, together with representatives of the Equalities and Human Rights Commission and the Healthcare Commission has been working since 2007 to drive progress on access to healthcare services for people with learning disabilities. This group will oversee delivery of the commitments in *Valuing People Now* around improving access to mainstream healthcare for people with learning disabilities. The group will now report to the Learning Disability Programme Board. The Group will have a particular focus on ensuring the commitments given in the Government's response to *Healthcare for All* and supporting regional and local progress in responding to the Inquiry.

JCHR recommendation

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 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)

Government response

Valuing People Now sets out the range of action being taken by the Department of Health, together with the NHS and other organisations, to address the ten recommendations of *Healthcare for All*, the report of the Independent Inquiry established to respond to the findings set out in *Death by Indifference*.

DH is working with the Equality and Human Rights Commission, the professional regulatory bodies and the commissioners and providers responsible for education and training of health and social care professionals, to help ensure that education and training reflects equality and human rights issues in general and the needs of people with learning disabilities in particular.

The new arrangements for annual health checks for people with learning disabilities include training for GPs and GP practice staff. Self advocacy organisations will feed into this training.

DH is committed to working with NHS organisations to help ensure there are wider systems in place, including arrangements for information sharing, communication and cross-boundary working, to ensure that people with a learning disability receive timely, convenient access to services that will address individual health needs. We will work with Strategic Health Authorities to review progress in making these improvements.

JCHR recommendation

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, there 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)

Government response

At the 60th Anniversary of the NHS, the Government reiterated its commitment that the provision of healthcare, free at the point of delivery is a fundamental human right, rather than a privilege.

The NHS Constitution proposed in Lord Darzi's report *High Quality care for all: NHS Next Stage Review*, enshrines the legal rights of individuals in relation to the NHS.

JCHR recommendation

31. 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)

Government response

We have consulted publicly upon proposals for registration requirements which the Care Quality Commission can enforce in line with the spirit of the relevant provisions of the European Convention on Human Rights. These proposed requirements would not confer any individual rights of legal redress under the Human Rights Act on people using registered health and social care services, but have been developed to ensure the Care Quality Commission has a clear remit to act against providers which fail to comply with legislation designed to protect people's human rights. We are currently analysing the responses to the consultation.

JCHR recommendation

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)

Government response

The Good Practice Guidance will support parents with learning disabilities and their children, and we recognise that widespread implementation depends on effective dissemination. To ensure that all local authority social services departments, children's services and NHS Trusts are aware of this guidance, we will disseminate it in the following ways:

- through the local authority/Government Office email sent directly from DCSF to all Directors of Children and Learners, Directors of Children's Services, Assistant Directors and other local authority staff;
- in an email sent to all local authority Parenting Commissioners who will be asked to share it with their counterparts in PCTs and NHS Trusts.

We will also explore options for this guidance to be part of updated guidance and information on Children's Centres and Extended Schools and guidance for local authorities on Children and Young People's Plans.

It is important that relevant professionals have training in the effective implementation of this guidance. DCSF and DH officials will work closely with local authorities, Government Offices of the Regions, and the National Academy of Parenting Practitioners (NAPP) to ensure that this is realised.

JCHR recommendation

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 lives. 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)

Government response

The *Valuing People Now* strategy sets out the key cross-government commitments to set the environment to enable change to happen, and summarises actions, based on good practice to grow capacity and capability for local delivery. Valuing People regional leads will work to develop the capacity of Partnership Boards to enable a robust collection of data locally to measure progress in delivering the strategy, including for parents with a learning disability.

JCHR recommendation

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)

Government response

Valuing People Now sets out the Government's commitment to making sure that people are kept as safe as possible, whilst being able to engage in normal activities in their lives. In particular, the strategy sets out measures to address hate crime against people with learning disabilities.

Key actions in this area include:

- DH working with local and national bodies to improve the reporting arrangements of crimes so that they are accessible to people with a learning disability;
- Supporting local good practise where people with learning disabilities are involved in training of the statutory organisation, such as the Police;
- The Home Office and DH will work together to make sure that the Hate Crime Strategy which includes disability Hate Crime addresses the specific issues for people with learning disabilities;
- Contributing to and support the implementation of the Crown Prosecution Service's new policy on prosecuting crimes against people with learning disabilities.
- Work within the criminal justice system (through the Ministry of Justice, Office of Criminal Justice Reform, Crown Prosecution Service and Association of Chief Police Officers) to update guidance and training on the identification of and support for vulnerable victims.

JCHR recommendation

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)

Government response

The Government will ensure that the views of people with a learning disability and their family carers are included in the consultation on the review of the *No Secrets* guidance on safeguarding vulnerable adults. The Consultation on the review of No Secrets has questions about the possibility of new legislation for safeguarding. The Government is encouraging a debate about whether and what type of legislation to consider. People with learning disabilities will benefit from the revised guidance which will follow, and if there is new legislation from that too.

JCHR recommendation

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)

Government response

With funding from Home Office, the Valuing People Support Team are developing a *Learning Together* training pack and good practice guidance which will helps local Learning Disability Partnership Boards, self advocacy Groups and Crime and Disorder Reduction Partnerships work together to combat crime against people with learning disabilities.

JCHR recommendation

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)

Government response

The Government is committed to providing accessible information in line with its obligations under the Disability Discrimination Act (2005) (DDA), including easyread summary documents where the audience would warrant it. DH will consider how to promote locally accessible information for people with learning disabilities, focusing on the NHS. A set of standards for producing and commissioning easier to understand information will be published in early 2009.

Similarly, Local Authorities must have regard to their obligations under the Disability Discrimination Act when delivering their duty to provide information to parents under section 12 of the Childcare Act 2006 – which requires them to establish and maintain a service providing information, advice and assistance to parents and prospective parents. The Children's Plan published in December 2007 set out a new goal that by 2020 parents would be satisfied with the information and support they receive. The Government is currently considering how progress towards this goal might be measured at a national level in a way that takes account of the different perspectives, experiences and needs of different groups of parents.

JCHR recommendation

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 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)

Government response

Putting People First and the Valuing People Now strategy emphasise the importance of ensuring that the right level of support, advice and information and advocacy is available to people with learning disabilities. The Office of the National Director for Learning Disabilities will commission a scoping study of training materials on human rights for people with learning disabilities; and will consider commissioning the development of additional training materials on human rights.

JCHR recommendation

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)

Government response

Valuing People Now emphasises the importance of including everyone, and in particular people who have more complex needs. This includes considering different means of communication to ensure that each individual can be engaged in the development of their own person centred plan. Valuing People Now recognises the importance of total communication and that the very particular support needs of an individual will mean very individualised support packages including systems for facilitating meaningful two-way communication to enable people to have social relationships and to participate in the community.

JCHR recommendation

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)

Government response

Some information is already collected on residential care out of area placements. The Commission for Social Care Inspection (CSCI) also collects information on out of area placements as an important source of information for regulation and planning for local commissioners.

Valuing People Now restates the importance of enabling people with learning disabilities to live locally and highlights good practice examples of where people have been brought home from out of area placements and supported to live independently.

Specific work is planned to ensure that Partnership Boards also collect information on out of area placements and work with CSCI to address inequalities. The Department of Health has issued 'Services for people with learning disability and challenging behaviour or mental health needs,' which provides best practice guidance and urges the use of personal budgets and a very individual approach to providing good local alternatives to out of area placements. The emphasis here is on good preventative person-centred commissioning and an important role for good local providers and specialist health services working in partnership.

JCHR recommendation

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)

Government response

Valuing People Now confirms a human rights approach as a key underpinning principle for public services to support people with learning disabilities live independently. It reemphasises that people with learning disabilities and their families have the same rights as everyone else, as enshrined in the Human Rights Act 1998 and Disability Discrimination Act (2005).



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