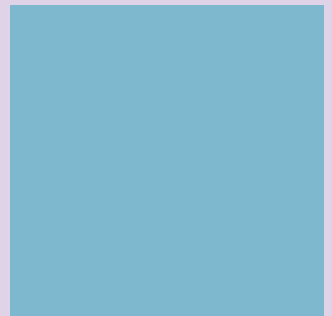


Valuing People Now: a new three-year strategy for people with learning disabilities

'Making it happen for everyone'



Valuing People Now: a new three-year strategy for people with learning disabilities

Making it happen for everyone



DH INFORMATION READER BOX

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Foreword by the Secretaries of State



Alan Johnson



Hazel Blears



Ed Balls



Liam Byrne



James Purnell



Geoff Hoon

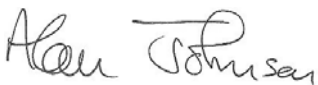
People with learning disabilities are entitled to the same aspirations and life chances as other people. This is the vision and expectation which the Government first set out in *Valuing People* in 2001. But although we have made real progress, there is still a lot to do – and that is why we are restating our commitment to leading change to transform people’s lives and opportunities. This Government is determined to deliver equality and independent living for all disabled people, as we made clear in our cross-Government report, *Improving the Life Chances of Disabled People* in 2005. Moreover, we recognise that people with learning disabilities are among the groups most often excluded from society. That is why we have made it a priority across government to support more people with learning disabilities into real jobs and settled homes.

The strategy is driven by the views of people with learning disabilities and their families and carers. The strategy and the delivery plan which is published alongside it set out the action we plan to take over the next three years, working with people with learning disabilities, their families and carers and with other partners.

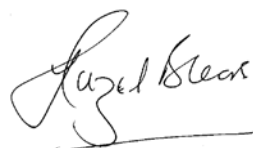
The strategy focuses on what needs to be done at all levels to deliver the vision of equality and transformed lives for everyone. It is rooted in the over-arching aim of designing and delivering public services and support which meet people’s individual needs. The transformation of public services will be critical to the delivery of *Valuing People Now*.

If people with learning disabilities and their carers are to have the same opportunities as other people in society and to lead a fulfilling life, we need to improve their access to the whole range of public services. This means improving health and social care support; ensuring that they are able to access education, work and leisure opportunities; and giving them the same opportunities as anyone else to live where they want, with whom they want and in safety. It means taking a human rights-based approach.

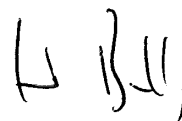
Alan Johnson



Hazel Blears



Ed Balls



Liam Byrne



James Purnell



Geoff Hoon



Foreword by the Minister for Care Services



Valuing People Now sets a challenge for public services and everyone who works with people with learning disabilities to take an approach which starts with each individual, their wishes, aspirations and needs, and which seeks to give them control and choice over the support they need and the lives they lead.

The main priorities that were set out for consultation in November 2007 have been restated in the new strategy. It starts from the principle that people with learning disabilities are people first. In seeking to deliver personalised support, the priorities are to enable people to take control of their lives, have employment and educational opportunities, have choice over what they do during the day, have better health, and have improved access to housing. However, the top priority of all is to make sure that change happens.

Change needs to happen for everyone with learning disabilities, including those with more complex needs, those from black and minority ethnic communities, those with autistic spectrum conditions and those who have offended. Families and family carers are also vital partners in the delivery of *Valuing People Now*.

Crucially, too, this strategy sets out the Government's response to the recommendations in the report of the Independent Inquiry into access to healthcare chaired by Sir Jonathan Michael, *Healthcare for All*, published on 28 July 2008. That report carried a hard-hitting, salutary message. It set out compelling evidence that people with learning disabilities have greater need for healthcare than other people, yet have worse access to the care that they need and poorer health outcomes. We are committed to improving healthcare access and health outcomes for people with learning disabilities. This is one of the key priorities in *Valuing People Now*.

Valuing People Now is about making it happen at a local level for all people – it needs the full commitment of the full range of service providers and agencies across all sectors to plan, review and commission strategically, and the full involvement of people with learning disabilities and family carers at all stages. I am delighted that the new National Director for Learning Disabilities will be leading delivery, and I look forward to making significant progress over the next three years in making this happen.

I'm delighted that Jonathan Shaw, the Minister for Disabled People, has agreed to co-sign this Foreword to demonstrate his commitment to improving the lives of people with learning disabilities.



Phil Hope

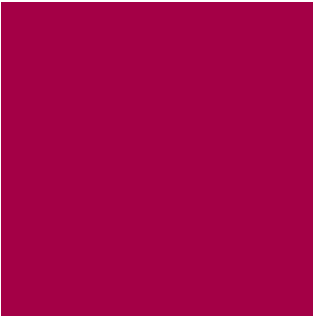
A handwritten signature in black ink that reads "Phil Hope".



Jonathan Shaw

A handwritten signature in black ink that reads "Jonathan Shaw".

Introduction by Anne Williams, National Director for Learning Disabilities



I was delighted to be appointed as the new National Director for Learning Disabilities, not just because I have long been passionate about improving the life chances of people with learning disabilities, but also because the work to refresh the Valuing People strategy is an opportunity to really make transformation happen. My predecessor as National Director did a tremendous amount to raise, within central government, awareness of the needs and wishes of people with learning disabilities, their families and carers. My aim is to build on what he achieved and lead the delivery of this new strategy.

It is really exciting that over 10,000 people were involved in responding to the consultation on *Valuing People Now* and that there was support for the guiding principles underpinning the strategy and endorsement of the policy objectives.

Above all, however, the message from individuals with learning disabilities and family carers is that they want to see a real difference in the range, quality and choice of support and care services available in every local area. They want us to ensure that everyone benefits from the implementation of *Valuing People Now*, including people with more complex needs, those from minority ethnic communities, people on the autistic spectrum and individuals who have offended. They also want us to recognise the importance and expertise of family carers. Our task therefore is to make the strategy happen, and make it happen for everyone, everywhere.

This will require the full involvement of individuals with learning disabilities and family carers. It will require leadership nationally across Government, regionally and especially from councils, directors of adult social services and chief executives of primary care trusts (PCTs) who are well placed to ensure that change happens locally. The voluntary and private sectors also have an important part to play in reshaping support and services.

My key task, with the Co-Director, and working with my new team, government officials, the deputy directors of social care and Valuing People leads in the regions, is to support local implementation.

I see partnership boards as being **central** to the strategic planning, commissioning, delivery and performance management of all services as they relate to learning disability in every local area. Well supported by directors of adult social services, lead members, PCT chief executives and

their non-executive directors, partnership boards need to be empowered to lead the implementation of *Valuing People Now*.

The Delivery Plan published alongside this strategy sets out roles and responsibilities, actions and milestones. Further best practice guidance and self-assessment tools for partnership boards will follow.

My measures of success at the end of three years will be if:

- the implementation of *Valuing People Now* secures improvements in the lives of all people with learning disabilities;
- all individuals have personalised, high-quality support and care plans;
- healthcare in communities, in hospitals and in specialist services improves;
- more people live in their own homes;
- more people have jobs;
- more people are able to live in their locality;
- the needs of people with the most complex needs are met in creative and personalised ways.

I look forward to the challenge of making it happen and to working with you all.



Anne Williams

A handwritten signature in cursive script that reads "Anne Williams".

Executive summary



- 1 *Valuing People Now: A new three-year strategy for people with learning disabilities* sets out the cross-government strategy for the next three years. In doing so, it takes account of the responses to the consultation, which ended in March 2008. In particular, this strategy:
- addresses what people have told us about the support people with learning disabilities and their families need;
 - reflects the changing priorities across government which impact directly on people with learning disabilities;
 - sets out the Government's response to the ten main recommendations in *Healthcare for All*,¹ the report of the Independent Inquiry into access to healthcare for people with learning disabilities, chaired by Sir Jonathan Michael; and
 - provides a further response to the Joint Committee on Human Rights report, *A Life Like Any Other?*²

The vision

- 2 The vision remains as set out in *Valuing People*³ in 2001: that all people with a learning disability are people first with the right to lead their lives like any others, with the same opportunities and responsibilities, and to be treated with the same dignity and respect. They and their families and carers are entitled to the same aspirations and life chances as other citizens. This vision sits firmly within the context of:
- the transformation of social care and the personalisation agenda set out in *Putting People First*;⁴
 - the Independent Living Strategy⁵ – a cross-government strategy for all disabled people; and
 - the Carers Strategy, *Carers at the heart of 21st-century families and communities*.⁶
 - *Aiming High for Disabled Children: transforming services for disabled children and their families*.⁷
 - *The Children's Plan: building brighter futures* (2007).⁸

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

2 *A Life Like Any Other? Human Rights of Adults with Learning Disabilities* (2008 HL Paper 40-1 HC 73-1) House of Lords, House of Commons, Joint Committee on Human Rights (2008)

3 *Valuing People: A New Strategy for Learning Disability for the 21st Century* (Cm 5086) Department of Health (2001)

4 *Putting People First: A shared vision and commitment to the transformation of Adult Social Care*, Department of Health (2007)

5 *Independent Living Strategy*, Office for Disability Issues (2008)

6 *Carers at the heart of 21st-century families and communities*, Department of Health (2008)

7 *Aiming High for Disabled Children: Better Support for Families*, HM Treasury/Department for Education and Skills (2007)

8 *The Children's Plan: building brighter futures*. DCSF CM7280 (2007).

Delivering the vision

- 3 The key focus of this strategy is to make that vision a reality. Each chapter, therefore, sets out key cross-government commitments and actions to set the environment to enable change to happen, and summarises local and regional actions, based on good practice to grow capacity and capability for local delivery. The key partners who will all play a crucial role in the delivery of *Valuing People Now* are set out below:

Key partners in delivery of *Valuing People Now*

- **Government departments:** the Departments of Health (DH), Children, Schools and Families (DCSF), Home Office, Communities and Local Government (CLG), Transport (DfT), Work and Pensions (DWP), Innovation, Universities and Skills (DIUS), Ministry of Justice (MoJ), and Cabinet Office (Office of the Third Sector (OTS)).
- **The National Directors for Learning Disabilities:** appointed by the Secretary of State for Health to lead on the delivery of *Valuing People Now* for the next three years. One is a person with a learning disability.
- **The Office of the National Director:** supports the two National Directors and provides expertise across a range of subject areas via a team of national leads.
- **The Valuing People team:** leads and supports the delivery of *Valuing People Now* at a local and regional level.
- **Government Offices of the Regions:** will lead on delivery across government in the nine regions.
- **Deputy Regional Directors for Social Care and Partnerships:** will lead on social care delivery in the nine regions.
- **Strategic health authorities (SHAs):** will set the strategic direction and performance manage primary care trusts (PCTs).
- **Directors of Adult Social Services:** have lead responsibility for commissioning the provision of social care services for people with learning disabilities.

- **Directors of Children Services:** have responsibility to link with adult services in the transition of young people with learning disabilities.
- **Chief executives of PCTs:** have the lead responsibility for commissioning healthcare services for people with learning disabilities.
- **Learning Disability Partnership Boards:** the 150 partnership boards bring together local partners including people with learning disabilities and their families.
- **National Forum for People with Learning Difficulties:** brings together representatives from nine regional forums for people with learning disabilities to inform government how Valuing People is working for people.
- **National Valuing Families Forum:** brings together representatives from nine regional family carers' networks to inform government how Valuing People is working for carers.
- **Third sector providers:** charitable and voluntary organisations which provide services for people with learning disabilities, including advocacy and peer support.
- **Independent providers:** organisations in the private and independent sector which provide services for people with learning disabilities.
- **Care Quality Commission (CQC):** will regulate organisations that provide health and social care services.

- 4 There is a well-established body of legislation and policy that already applies to service providers in relation to people with learning disabilities and their families, in particular the Disability Discrimination Act (2005) and the Human Rights Act (1998). This strategy does not place many **new** burdens on services or frontline staff; rather it is about emphasising what best practice looks like and identifying the key levers to enable this best practice to become universal.

The key messages

- 5 This strategy is written from a human rights based approach, on the fundamental principle that people with learning disabilities have the same human rights as everyone else, and sets out further steps for this

to happen. It responds to the concerns set out in the Joint Committee on Human Rights report *A Life Like Any Other?* that adults with learning disabilities are particularly vulnerable to breaches of their human rights.

Chapter 1: Including everyone

- 6 The strategy has been strengthened to ensure that it is inclusive of those groups who are least often heard and most often excluded. This reflects concerns expressed by respondents to the consultation on *Valuing People Now* that service providers, commissioners and policy makers were not specifically addressing the needs of these groups, including:
 - people with more complex needs;
 - people from black and minority ethnic groups and newly arrived communities;
 - people with autistic spectrum conditions; and
 - offenders in custody and in the community.
- 7 DH will take forward programmes of work around ethnicity and complex needs and with families. These will be underpinned by regional and local action to support partnership working, particularly through Learning Disability Partnership Boards. We have worked closely with family carer groups to ensure that this strategy reflects the concerns they raised during the consultation – that they be seen as expert partners in the care of their loved ones and that the particular needs of people with more complex conditions are met.

Chapter 2: Personalisation

- 8 Person centred planning, advocacy and direct payments to give people more choice and control in their lives were at the heart of the original *Valuing People*. In December 2007, the cross-sector concordat *Putting People First* set out a vision for transforming social care. At its heart is the commitment to giving people more independence, choice and control through high-quality and personalised services. *Putting People First* is about empowering people to shape their own lives and the support they receive by allowing them to use resources more flexibly to suit their needs and lifestyle.
- 9 Delivery of this vision will depend upon central and local government working together with partners across the sector. *Putting People First*

recognises that services across transport, leisure, education, health, housing, community safety and the criminal justice system and access to information and advice are vital to ensuring people's independence and overall quality of life.

- 10 For people with learning disabilities and their families, transformation should mean using person centred approaches (such as person centred planning and support planning) and improved outcomes in terms of social inclusion, empowerment and equality. More people with learning disabilities should be able to commission their own services to live independently and have real choice about the way they live their lives. The Government will take action to ensure that this transformation programme includes the needs of people with learning disabilities and their carers.

Chapter 3: Having a life

Health

- 11 Better health for people with learning disabilities is a key priority. There is clear evidence that most people with learning disabilities have poorer health than the rest of the population and are more likely to die at a younger age. Their access to the NHS is often poor and characterised by problems that undermine personalisation, dignity and safety. The final report of the NHS Next Stage Review⁹ sets out the vision for the NHS that it will 'deliver high quality care for **all** users of services in all aspects'. Key issues for the NHS are to achieve full inclusion of people with learning disabilities in mainstream work to reduce health inequalities and to ensure high-quality specialist health services where these are needed.
- 12 The report of the Independent Inquiry into access to healthcare for people with learning disabilities, *Healthcare for All*, was published in July 2008 and made 10 key recommendations for improvement. This strategy sets out a programme of work to address *Healthcare for All* recommendations.
- 13 People with learning disabilities are entitled to be treated with the same dignity and respect as any other member of the community. Neglect or abuse of disabled people is absolutely unacceptable and the Government

9 *High Quality Care for All: NHS Next Stage Review Final Report (CM 7432)*, Department of Health (2008)

is determined that lessons are learnt and that action is taken to improve healthcare for people with learning disabilities.

Housing

- 14 This strategy builds on existing programmes including Supporting People¹⁰ to increase the housing options available to people with learning disabilities. Many people with learning disabilities do not choose where they live or with whom. More than half live with their families, and most of the remainder live in residential care. The Government will deliver a programme of work to ensure that mainstream housing policies are inclusive of people with learning disabilities.

Work, education and getting a life

- 15 People with learning disabilities want to lead ordinary lives and do the things that most people take for granted. They want to study at college, get a job, have relationships and friendships and enjoy leisure and social activities.
- 16 Under *Aiming High for Disabled Children*, the Transition Support Programme will work to support local areas to improve transition arrangements across children's health and social care, including consolidating person centred approaches for people with learning disabilities. Adult services have an important role as equal partners in transition. This work will address the concerns of families and young people that the transition from childhood to adulthood is difficult and they feel excluded from decisions.
- 17 A cross-government employment strategy will be published in Spring 2009, which includes a significant expansion of employment opportunities for people with learning disabilities. This will be linked to the Public Service Agreement (PSA) 16 delivery plan on increasing the number of adults with learning disabilities in employment. The cross-government Work, Education and Life Group will also lead implementation of '*Progression through Partnership*'¹¹ (the post-16 education strategy) and the Getting a Life project, which aims to achieve an integrated assessment and decision-making process that will allow

10 The Supporting People programme funds local authorities to provide services which help vulnerable and older people to live independently. See *Independence and Opportunity: Our Strategy for Supporting People*. Department for Communities and Local Government. June 2007. www.communities.gov.uk/publications/housing

11 '*Progression through Partnership*': A Joint Strategy between the DfES, DH and DWP on the role of Further Education and Training in Supporting People with Learning Difficulties and/or Disabilities to Achieve Fulfilling Lives, The Stationery Office (2007)

people to use public resources flexibly to get the outcomes they want, including access to employment opportunities.

Relationships and having a family

- 18** This strategy emphasises the importance of enabling people with learning disabilities to meet new people, form all kinds of relationships, and to lead a fulfilling life with access to a diverse range of social and leisure activities. It also emphasises their right to become parents and the need for adequate support to sustain the family unit. There is evidence that people with learning disabilities have limited opportunities to build and maintain social networks and friendships. Parents with a learning disability do not get sufficient access to support, putting families at risk of enforced separation. However, Sure Start Children's Centres work together with other professionals to help parents with learning disabilities and their children receive the right emotional and practical support to meet the assessed needs of the child and family.

Chapter 4: People as citizens

Advocacy

- 19** *Putting People First* recognises the importance of ensuring the right level of support, information and advice and advocacy is available to people, including those with learning disabilities.
- 20** The Valuing People national advocacy fund will focus on supporting advocacy to achieve a greater impact. The programme includes:
- a quality tool for self-advocacy groups;
 - work to better support advocacy for people from black and minority ethnic communities and people with complex needs; and
 - strengthening leadership support for people with learning disabilities.

Transport

- 21** DfT and DH will ensure national programmes on inclusive transport include people with learning disabilities. We know that people with learning disabilities are less likely to make journeys than non-disabled people because of transport difficulties.

Leisure services and social activities

- 22 DH will work with the Department for Media, Culture and Sport to explore how local services can be made more accessible for people with learning disabilities. This is to address concerns that people with learning disabilities are often not connected to their communities or given meaningful vocational, social, leisure or learning activities.

Being safe in the community and at home

- 23 The Home Office will work with DH, the Ministry of Justice (MoJ) and related crime and disorder agencies and third sector partners to support the development and implementation of the Disability Hate Crime Strategy, making sure the specific issues for people with learning disabilities are addressed. This recognises that the lives of people with learning disabilities are still constrained by experience of abuse and neglect. Many people do not feel safe in their local communities and have been victims of hate crime.
- 24 DH will publish revised *No Secrets* guidance on safeguarding vulnerable adults following consultation,¹² including consultation with people with learning disabilities.

Access to justice and redress

- 25 The Crown Prosecution Service is developing a new policy on prosecuting crimes where people with learning disabilities are victims or witnesses. Valuing People regional leads will support partnership boards to engage with local crime and disorder partnerships to help people with learning disabilities and their families understand their rights and how to complain. This will help address concerns that people with learning disabilities are less likely to report a crime or take part in the criminal process as a witness, because they may lack the confidence or support to speak out and find processes complex. They may also have low expectations. Where young people with learning disabilities are in custody, the Youth Crime Action Plan provides for improved education and training.¹³

12 *Safeguarding Adults: A Consultation on the Review of the 'No Secrets' Guidance*: www.dh.gov.uk/en/Consultations/Liveconsultations/DH_089098

13 *The Youth Crime Action Plan* (2008) available at www.homeoffice.gov.uk/documents/youth-crime-action-plan/

Chapter 5: Making it happen

- 26** The delivery of this strategy needs to be rooted within the mechanisms and processes established to deliver the wider health and social care transformational agenda – in particular, Joint Strategic Needs Assessments, Local Strategic Partnerships, Local Area Agreements and partnership boards.
- 27** The National Directors will lead the delivery programme for *Valuing People Now*. The Government will continue to support and strengthen the national mechanisms to drive delivery, including:
- the National Forum of People with Learning Difficulties;
 - the National Valuing Families Forum; and
 - a new national Learning Disability Programme Board.
- 28** A key element of delivery will be the development of capacity and capability at local levels to design and commission the support services that people need to enable them to live independently and close to their families and friends. Local partnership with people with learning disabilities and their families will be crucial to this, and Learning Disability partnership boards have a vital role to play. The Valuing People team will develop tools to support local action to deliver transformation and support provision of robust data sets to inform local action, and enable partnership boards to benchmark progress. The National Directors and Valuing People team will target support on those areas which are underperforming and encourage good partnership boards to mentor poor performers. Directors of adult social services, PCT chief executives and local authority elected members have an important role to play. Third sector and independent sector providers will be vital to delivering this vision.
- 29** The responsibility for commissioning and funding social care for people with learning disabilities will transfer from the NHS to local government from April 2009 in line with guidance issued to local authorities and PCTs.¹⁴
- 30** The Office of the National Director will work with government departments to support the development of staff who work to deliver support for people with learning disabilities within the context of the National Adult Social Care Workforce Strategy to be launched in 2009.

¹⁴ *Valuing People Now: Transfer of the responsibility for the commissioning of social care for adults with a learning disability from the NHS to local government and transfer of the appropriate funding* (2008): www.dh.gov.uk/en/Publicationsandstatistics/Lettersandcirculars/Dearcolleagueletters/DH_087148

- 31 A detailed delivery plan is being published alongside this strategy and we will produce a summary position statement setting out how the existing performance frameworks relate to provision of services for people with learning disabilities in Spring 2009.



Principles

- 32 The new strategy reaffirms the four guiding principles set out in *Valuing People* which apply to both individuals and services:

Rights:

- People with learning disabilities and their families have the same human rights as everyone else.

Independent living:

- This does not mean living on your own or having to do everything yourself. All disabled people should have greater choice and control over the support they need to go about their daily lives; greater access to housing, education, employment, leisure and transport opportunities and to participation in family and community life.

Control:

- This is about being involved in and in control of decisions made about your life. This is not usually doing exactly what you want, but is about having information and support to understand the different options and their implications and consequences, so people can make informed decisions about their own lives.

Inclusion:

- This means being able to participate in all the aspects of community – to work, learn, get about, meet people, be part of social networks and access goods and services – and to have the support to do so.

Key policy objectives for 2009–12

33 The strategy sets out key policy objectives for the next three years:

All people with learning disabilities and their families will:

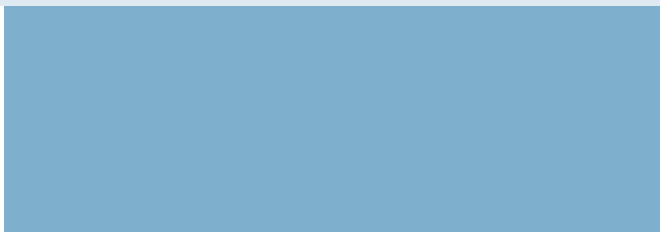
1. benefit from *Valuing People Now*;
2. have greater choice and control over their lives and have support to develop person centred plans;
3. get the healthcare they need and the support they need to live healthy lives;
4. have an informed choice about where, and with whom, they live;

5. have a fulfilling life of their own, beyond services, that includes opportunities to study, work and enjoy leisure and social activities;
6. be supported into paid work, including those with more complex needs;
7. have the choice to have relationships, become parents and continue to be parents, and will be supported to do so;
8. be treated as equal citizens in society and supported to enact their rights and fulfil their responsibilities;
9. have the opportunity to speak up and be heard about what they want from their lives – the big decisions and the everyday choices. If they need support to do this, they should be able to get it;
10. be able to use public transport safely and easily and feel confident about doing so; and
11. be able to lead their lives in safe environments and feel confident that their right to live in safety is upheld by the criminal justice system.

For services:

1. Leadership, delivery and partnership structures are put in place that will make sure the outcomes set out in this strategy are delivered.
2. Effective commissioning in a way that best supports the right outcomes for people with learning disabilities and their families is ensured.
3. The workforces across services are given the appropriate support and training to equip them with the values, skills and knowledge to deliver the *Valuing People Now* priorities for all people with learning disabilities.
4. Learning disabilities will have a clear position in the new performance frameworks for the NHS and local authorities, and there will be a comprehensive range of data sets and reporting mechanisms.

Introduction



Background – existing policy

- 1 *Valuing People: A New Strategy for Learning Disability for the 21st Century*¹⁵ was the first policy that signalled a new approach to the delivery of care, and a new relationship between the State and the citizen. It provided a vision for the lives of people with learning disabilities and their families based on the four principles of rights, independence, choice and inclusion. It sought new ways to give people and families a voice, to be at the centre of their own plans, and to have some control over how resources were spent on them through Direct Payments. This approach was extended through the InControl¹⁶ pilots. *Valuing People* has a currency beyond England and has set the standard for other countries.
- 2 This was taken further in the cross-Government concordat, *Putting People First* (2007) which set out plans for ‘collaboration between central and local government, professional leadership, providers and the regulator in developing a future for social care services that supports people to live independently, stay healthy and have the best possible quality of life, irrespective of illness and disability’.¹⁷ As part of this, it confirmed a shift in emphasis towards greater **personalisation** of services, including a greater focus on person centred approaches and personal budgets over the next few years. Lord Darzi’s report on the future of the National Health Service¹⁸ drew on this personalised approach to consider the way health services are commissioned and delivered as part of a wider partnership between health, social care and local communities.
- 3 *Valuing People Now* is a new three-year strategy to take forward the implementation of the policy set out in *Valuing People* in this wider developing social policy context.

Why a new strategy?

- 4 In 2001 *Valuing People* stated that in England there were approximately 210,000 people with a severe and profound learning disability, of whom 65,000 were children and young people, 120,000 of working age,

15 *Valuing People: A New Strategy for Learning Disability for the 21st Century* (Cm 5086), Department of Health (2001)

16 In Control: www.in-control.org.uk/site/INCO/Templates/Home.aspx?pageid=1&cc=GB

17 *Putting People First: A shared vision and commitment to the transformation of Adult Social Care*, Department of Health (2007)

18 *High Quality Care for All: NHS Next Stage Review Final Report* (CM 7432), Department of Health (2008)



and 25,000 older people. Additionally it was estimated that a further 1.2 million people had a mild or moderate learning disability.

- 5 In 2004, a research paper from the Institute for Health Research at Lancaster University estimated that there were 985,000 people with learning disabilities, including 190,000 aged under 20, 127,000 aged 65 or over, and 795,000 adults (defined as over 20 and under 65).¹⁹ Of these, 224,000 were people in England known to social services. The remaining 761,000 people had mild to moderate learning disabilities, may not be known to services, and may not need very much additional support beyond their own families, friends and social networks. However, without information about and access to a range of mainstream services, and help at points of crisis, their needs may escalate to the point where their support networks break down. Emerson and Hatton also estimated that the total number of adults with a learning disability (aged 20 or over) will increase by 8% to 868,000 in 2011 and by 14% to 908,000 by 2021. Significantly all the growth projection shows much higher increases in the number of adults aged over 60.²⁰
- 6 A paper from the Centre for Disability Research published in November 2008²¹ looks at the numbers of people with learning disabilities using social care services. This estimates that the number of adults with

19 See Eric Emerson and Chris Hatton, *Estimating Future Need/Demand for Supports for Adults with Learning Disabilities in England* Institute for Health Research at Lancaster University (2004)

20 See Eric Emerson and Chris Hatton (2004)

21 See *Estimating Future Need for Adult Social Care Services for People with Learning Disabilities in England*, Eric Emerson and Chris Hatton, Centre for Disability Research (2008)

learning disabilities known to services in 2006/07 was 187,000 while those using services was 137,000. Further, it estimates that there are currently 147,000 using services. The implication of the research is that more people with mild to moderate disabilities will become known to, and start using, services. Thus, the numbers of people using services is set to increase by more than 50% by 2018 to 223,000.

7 Since *Valuing People* in 2001, considerable progress has been made:

- many people with learning disabilities now have a voice through the development of advocacy, the Regional and National Forums, and person centred planning;
- family carers have a stronger voice through regional carers networks, the new National Valuing Families Forum, and more carers' assessments;
- leadership training like Tomorrow's Leaders and Partners in Policymaking has helped develop strong self-advocate and family carer leaders in many places;
- some people have person centred plans that have made a positive difference to their lives;



- InControl has shown that person centred planning leads to better outcomes if the money comes with it through a personal budget;
- over 2,000 people with learning disabilities have Direct Payments;
- more people are living in homes of their own, either in tenancies or through home ownership;
- the old long-stay hospitals (with one exception) have been closed and most of the people who moved in the last wave of transfers are in supported living rather than residential care;
- a few more people have paid work and many more people have opportunities to do things in the daytime other than attend day centres;
- in some areas people have health action plans that have improved their access to health services;
- there are a few examples of people with complex needs benefiting from these developments;
- there is a Learning Disability Partnership Board in every local authority area and people with learning disabilities and family carers have places at these boards;
- some boards have developed successful strategies for implementing *Valuing People* locally.

8 However, seven years on from *Valuing People* much remains to be done:

- the Social Exclusion Task Force identified people with moderate and severe learning disabilities as one of the most excluded groups in our society;
- only 15% of people have a home of their own;
- more than 30% of people with learning disabilities live in residential care homes, a significant proportion of which are miles away from their place of origin and their families;
- many people with learning disabilities are living with older family carers who have their own needs;
- only one in ten of those known to social services has any form of paid employment, and of those only very few work more than 16 hours a week;²²

- people with learning disabilities report that they are often the target of hate crime, that they are dependent on very limited and expensive public transport to get around, and that being lonely is one of the things they fear the most;
- the 2008 report of the Parliamentary Joint Committee on Human Rights, *A Life Like Any Other?*,²³ highlighted continued and extensive failure of services and society to accord people with learning disabilities their basic rights;
- *Healthcare For All*,²⁴ the report of the Independent Inquiry into access to healthcare for people with learning disabilities, reported significant and ongoing inequalities in access to healthcare services and in the quality of services.

9 The *Valuing People Now*²⁵ consultation which completed in March 2008²⁶ gave important messages about what needs to be done. This strategy has been written in the light of the responses to the consultation document and meetings with key stakeholders to reflect the key messages – in particular to:

- emphasise the vital role played by family carers;
- address ways of helping people with complex needs benefit from all of the proposals;
- improve knowledge and understanding about the wishes and needs of people with learning disabilities and their families from different cultures and ethnic communities, and so offer more appropriate support;
- ensure that all agencies are rigorous in making change happen and monitoring progress effectively;
- address issues around relationships and transport; and
- recognise that many people with learning disabilities need support for the whole of their lives.

23 *A Life Like Any Other? Human Rights of Adults with Learning Disabilities* (2008 HL Paper 40-1 HC 73-1), House of Lords, House of Commons, Joint Committee on Human Rights (2008)

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

25 *Valuing People Now: From progress to transformation*, Department of Health (2007)

26 A summary of the response to the consultation, *Summary of responses to the consultation on Valuing People Now: From progress to transformation* is available at www.dh.gov.uk/consultations

- 10 The strategy cannot operate in isolation. As well as the developing social care transformation programme embodied in *Putting People First*, the strategy sits firmly in the context of:
- Lord Darzi’s Next Stage Review of the NHS;
 - the Government Public Service Agreement (PSA) to measure the numbers of people with moderate and severe learning disabilities known to councils moving into settled accommodation and paid employment;²⁷
 - the Government’s *Independent Living Strategy*;²⁸
 - the National Carers Strategy;²⁹
 - Aiming High for Disabled Children: better support for families;³⁰
 - The Children’s Plan;³¹
 - the Government response to the DWP consultation on disability employment services;³²
 - the DWP Green Paper on Welfare Reform;³³
 - *‘Progression through Partnership*,³⁴ a commitment from four government departments to work together to synchronise responsibilities, systems and services to improve post-16 education opportunities for people with learning disabilities;
 - the consultation on *No Secrets* on safeguarding vulnerable adults;³⁵ and
 - our ambition to ratify the UN Convention on Disability Rights in spring 2009.

27 See definition of PSA 16 on page 80

28 *Independent Living Strategy*, Office for Disability Issues (2008)

29 *Carers at the heart of 21st-century families and communities*, Department of Health (2008)

30 *Aiming High for Disabled Children: better support for families*, HM Treasury/Department for Education and Skills (2007)

31 *The Children’s Plan: building brighter futures*. DCSF CM7280 (2007)

32 *Helping people achieve their full potential: Improving Specialist Disability Employment Services consultation – Summary of Responses*, Department for Work and Pensions (2008)

33 Green Paper *No one written off: reforming welfare to reward responsibility*, Department for Work and Pensions (2008); White Paper *Raising expectations and increasing support: reforming welfare for the future*, Department for Work and Pensions (December 2008)

34 *‘Progression through Partnership’: A Joint Strategy between the DfES, DH and DWP on the role of Further Education and Training in Supporting People with Learning Difficulties and/or Disabilities to Achieve Fulfilling Lives*, The Stationery Office (2007)

35 *Safeguarding Adults: A Consultation on the Review of the ‘No Secrets’ Guidance*: www.dh.gov.uk/en/Consultations/Liveconsultations/DH_089098

The four guiding principles

- 11 The starting point for the new strategy is the re-affirmation of the four guiding principles set out in *Valuing People*:

Rights:

- People with learning disabilities and their families have the same human rights as everyone else.

Independent living:

- This does not mean living on your own or having to do everything yourself. All disabled people should have greater choice and control over the support they need to go about their daily lives; greater access to housing, education, employment, leisure and transport opportunities and to participation in family and community life.

Control:

- This is about being involved in and in control of decisions made about your life. This is not usually doing exactly what you want, but is about having information and support to understand the different options and their implications and consequences, so people can make informed decisions about their own lives.

Inclusion:

- This means being able to participate in all the aspects of community – to work, learn, get about and meet people, be part of social networks and access goods and services – and to have the support to do so.

A human rights approach

'I don't know much about the convention on 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.'

Evidence from person with learning disabilities to the Joint Committee on Human Rights



- 12 The Joint Committee on Human Rights report, *A Life Like Any Other?*³⁶ found that adults with learning disabilities are particularly vulnerable to breaches of their human rights. It recommended 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.
- 13 The Government response to the Joint Committee set out where the Government is already taking 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 1998.³⁷ The Government agreed to provide the Joint Committee with a further response when it responded to the consultation on *Valuing People Now*. This is being published as a separate document alongside this strategy.
- 14 This strategy promotes a human rights based approach and the rights set out in the UN Convention on Human Rights. It confirms that adults with learning disabilities have, and should be able to enjoy on an equal basis, the same human rights as everyone else. It sets out the further steps that are needed for people with learning disabilities to achieve

36 *A Life Like Any Other? Human Rights of Adults with Learning Disabilities* (2008 HL Paper 40-1 HC 73-1), House of Lords, House of Commons, Joint Committee on Human Rights (2008)

37 www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyandGuidance/DH_084614

freedom, respect, equality, dignity and autonomy in their everyday lives. This includes action to:

- promote human rights in healthcare through promoting good practice;
- support independent advocacy to achieve a greater impact for people with learning disabilities, including people from black and minority ethnic communities and those with complex needs;
- address the specific issues for people with learning disabilities on safeguarding in the *No Secrets* consultation;
- reduce hate crime towards people with learning disabilities;
- address issues around social exclusion, poverty and isolation; and
- promote the involvement of people with learning disabilities and family carers in all aspects of local, regional and national workforce planning and delivery.

15 Underpinning this approach is the expectation that services delivering support to people with learning disabilities will act to ensure they are fully compliant with the law, especially the Human Rights Act 1998 and the Disability Discrimination Act 2005, and are mindful of the requirements of the UN Convention. The Disability Equality Duty within that Act requires public bodies to check the impact of their policies on the lives of disabled people – especially where the outcomes for people with learning disabilities are worse than for the population as a whole (eg health, employment, housing).

16 For all of us, rights come with responsibilities. Citizenship is also about contributing to society, in whichever way we can. People with learning disabilities have traditionally been viewed as recipients of care and of services. But they, too, have a role to play as contributors. Wherever possible, people with learning disabilities should be supported to work, pay taxes, vote, do jury duty, have children, and participate in community activities or faith groups. Many people with learning disabilities in using direct payments or personal budgets will contribute to the economy by becoming employers. All these things benefit the wider society.

Chapter 1: Including everyone



Overall policy objective: All people with learning disabilities and their families will benefit from *Valuing People Now*.

Valuing ALL people

1.1 The vision of *Valuing People Now* is that all people with learning disabilities are supported to become empowered citizens. It has to be inclusive of those groups that are generally most excluded. It is important that this includes:

- people with more complex needs;
- people from black and minority ethnic groups and newly arrived communities;
- people on the autistic spectrum; and
- offenders in custody and the community.

1.2 In service transformation, providers, commissioners and policy makers need to focus on those who are traditionally most likely to be left out. Often this will mean making specific adjustments to ensure that their particular needs are met.

People with 'more complex needs'

'If services develop communication and accessibility for ... people [with the most complex needs] they are probably getting it right for most people with learning disabilities.' Response to the consultation

Definition: In this strategy the term 'complex needs' is used to describe a range of multiple and additional needs that people with learning disabilities may have. This can include people with profound and multiple learning disabilities³⁸ and people whose behaviour presents a challenge. However, people's needs are not fixed; they may develop more complex needs in later life or may display less 'challenging' behaviour once appropriate support is given.

1.3 For people with more complex needs equality of access and opportunity usually means that specific adjustments need to be made and this may include very specialised support, both intense and ongoing. However, lack of understanding and aspiration about what can be achieved sometimes leads to an assumption that people will be passive recipients

38 See Mencap's fact sheet on people with profound and multiple learning disabilities: www.mencap.org.uk/

of care throughout their lives, as opposed to people who can make decisions and live as empowered citizens in our society.

- 1.4** The vision for people with more complex needs is the same as for everyone: inclusion and participation in all areas of community life, including living independently and having paid work. To assume that some people cannot, and will never, achieve these is to set a ceiling on what progress can be made, both by an individual and by a society.

Project Search high school transitions programme

Project Search is a year-long internship model developed in Ohio with proven success in getting people with moderate and severe learning disabilities into paid work and keeping them there.

A college tutor and job coaches run a programme of work training for interns via a series of real work placements in the host employer organisation. The project team are based in the employer organisation but the only financial cost to the employer is some staff time, providing a training room and desk space: the interns are unpaid and remain on government benefits during the scheme. The tutor and job coaches are paid for by bringing together funding the intern would have received from the educational and vocational support programmes.

The model has been established for 13 years and runs successfully in various large American and world-wide organisations, including Cincinnati Children's Hospital, several smaller hospitals and the Fifth Third Bank. Many of the interns secure and retain full-time paid employment with the host organisation; the others complete the programme and leave with skills that can be used in other work environments. They are generally supported by a job coach to secure employment elsewhere.

The model has now been adopted in Leicester and Norwich, with Remploy providing the job coaches, Leicester College and City College Norwich providing the tutors and some start-up costs in Norwich funded by Norfolk County Council. Leicester City Council, Leicester College and Norfolk and Norwich University Hospital are the host employers.

- 1.5** However, it has to be recognised that for some people with highly complex needs, such as those with profound and multiple learning disabilities or who are medically dependent, paid employment poses particular challenges, although it remains an aspiration. Appropriate and skilled support is required to enable them to participate in community life as fully as possible; and enabling them to lead fulfilling lives with opportunities for growth, relationships, decision-making and self-expression will also define them as equal citizens. Person centred planning is at the heart of this, and innovative ideas and practice, such as Circles of Support can facilitate this.

Circles of Support: Christian's story

'A circle of support, sometimes called a circle of friends, is a group of people who meet together on a regular basis to help somebody accomplish their personal goals in life.'

www.circlesnetwork.org.uk/circles_of_support.htm



Christian has very complex needs, including many health and communication challenges. His circle began when he was at school, after his mum attended some training as part of the CREDO East project, paid for by their local authority.

The people in Christian's circle are all volunteers and come from all walks of life: family friends, taxi drivers who used to take him to school, professionals who have come in and out of his life and some of his sister's friends. They were all people that Christian's family thought he liked, eg people who he made eye contact with or was comfortable sitting next to. His circle get to know him through spending social time with him and his family to understand his history and experiences, and by using objects of reference and some intensive interaction.

The circle's main purpose is to support Christian in drawing up plans about moving forward in life and being there with him to make sure that he achieves as much as possible. Christian's first PATH (planning alternative tomorrows with hope) was focused on transition from school, finding his own place to live and setting up his direct payments. Everything was achieved, and his new PATH is all about relationships and community connecting.

Christian's circle has supported him to have more social opportunities. He is a young man at great risk of social exclusion and isolation and this helps minimise these risks. The circle provides advocacy and friendship, and adds a dimension to creative planning and problem solving. It also provides a source of energy which is sometimes difficult for a family alone to sustain. One of the most powerful benefits of having a circle was seen when Christian was very ill and members stood around his hospital bed to ensure that he was offered appropriate treatment.

'Christian benefits immensely from his circle. We have helped him to create the kind of network that people without his complex disability make naturally through work, education and leisure. It is wonderful to see a group of people gathering around Christian, who does not use words or signs, and really try to walk in his shoes, be truly centred on him and be positive and creative.' Christian's mum

For information about the CREDO project and the Circles Network go to: www.circlesnetwork.org.uk/east_region.htm

- 1.6** Addressing the issues for people with complex needs is really about embedding the principles of personalisation within all aspects of planning, commissioning and delivery of support services. It is also about recognising that the very particular support needs of an individual will mean very individualised support packages, including systems for facilitating meaningful two-way communication.

Intensive interaction: facilitating two-way communication

Intensive interaction³⁹ is an approach to facilitating two-way communication with children and adults with severe or profound learning disabilities and/or autism, who are still at an early stage of communication development. It can be used to teach people fundamental communication or to provide them with a means to enjoy being expressive and feeling connected.

Building on the concept of augmented mothering (developed by the psychologist Gary Ephraim), Melanie Nind and Dave Hewett identified some key features of basic communication that occur between a mother and her child. The 'interactive style is modelled on the nurturing style of caregiver-infant interaction and is used with intensity and critical reflection.'⁴⁰

Intensive interaction is a practical approach to facilitating communication. The person with a learning disability works with their communication partner who adopts an interactive style, for example:

- altering voice or gaze or body language to appear less threatening and more interesting; and
- responding to the things a person with a learning disability does; letting them 'take the lead' by commenting on their actions, joining in with them, playfully imitating them.

While the evidence of this approach's success is mainly a small sample of case studies, it does point to increased socially interactive behaviour, eg greater use of eye contact; increased toleration of, or engagement in, physical contact activities; additional episodes of sustained joint attention; increased use of potentially communicative vocalisations; and an increased regard for facial signalling. There is also evidence in some cases that people have started to initiate communication and social interaction.

For more information see:

www.intensiveinteraction.co.uk/about/what.php

www.leedsmentalhealth.nhs.uk/ldservices/intensiveinteraction.cfm

39 *Access to Communication: Developing the basics of communication with people with severe learning difficulties through Intensive Interaction* Nind, M and Hewett, D (1994)

40 Nind, 2000, taken from an abstract presented at ISEC 2000: Special Schools, Intensive Interaction and Inclusion

1.7 Good services for people with complex needs:

- start with person centred planning, and with the assumption that everyone can benefit from direct payments and personal budgets;
- develop and use appropriate communication systems where people have little or no verbal communication, taking guidance from families and friends to understand what gestures or sounds may mean;
- do not assume that behaviours that seem challenging are simply part of a person's disability; we know that these behaviours serve a function for the individual and it is essential to identify what that function is. Often these behaviours are the only way that individuals have of communicating that their needs are not being met and it is essential to address this – ignoring them may put lives at risk;
- work with risk, constructively recognising that people develop and grow as they are supported to take on more responsibility;
- start with planning for people with the most complex needs, addressing what **additional and improved** services and supports are needed so that they can be included with everyone else, and not assigned to separate or segregated services;
- start with one person at a time in radical change initiatives – a few success stories can break down attitudinal barriers;
- fully involve families and carers in discussions and decision making from the beginning; and
- provide access to specialised support and services close to home where needed, alongside more mainstream support or as part of an inclusive and individualised package.

1.8 Resources are available to support development of local services which meet this vision. These include good practice guidance on *Services for People with Learning Disability and Challenging Behaviour or Mental Health Needs* (Mansell 2),⁴¹ which explains how to develop individualised responses for people who challenge services, and *Commissioning Specialist Adult Learning Disability Health Services*.⁴² In developing services locally, it is important to address participation in the local community as above.

41 *Services for People with Learning Disability and Challenging Behaviour or Mental Health Needs* (Mansell report, revised edition), Department of Health (2007): www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_080129

42 *Commissioning Specialist Adult Learning Disability Health Services: Good Practice Guidance*: www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_079987

1.9 Tailoring care and support for people with complex needs requires imagination, skill and commitment from the staff who provide support to people and the managers who employ those staff. There is clear evidence that where skilled person centred approaches are used, people with complex needs benefit. This requires more emphasis in workforce development so that individuals, families and local authorities helping them commission services can get the skilled support they need.

People from black and minority ethnic groups and newly arrived communities

1.10 People with learning disabilities from black and minority ethnic groups and newly arrived communities and their families often face what is called 'double discrimination'. They experience insufficient and inappropriate services. This may be caused by:

- policy and services which are not always culturally sensitive;
- wrong assumptions about what certain ethnic groups value;
- language barriers; and
- discrimination.

Yet evidence shows that increasing numbers of children and young people from black and minority ethnic communities are being identified as having special educational needs and more profound disabilities.



- 1.11** The Race Relations (Amendment) Act (2000) requires all services to be compliant and public authorities must monitor their work for any adverse effect on race equality. This means that all actions and initiatives described in this strategy should be assessed for their impact on minority ethnic communities. However, 48% of partnership boards who responded to a survey (54%) in 2006/07 said that no race equality impact assessment had been undertaken – either for the board itself or as part of a wider equalities impact assessment. And a recent review of partnership boards indicated that only 17% of partnership boards involved families from black and minority ethnic communities.⁴³
- 1.12** In some rural areas there are small numbers of people from black and minority ethnic groups and newly arrived communities and they can be less visible. This can mean that services do not meet people’s needs. Guidance on working with people from minority ethnic groups in rural areas can help local service planners and developers address this.⁴⁴
- 1.13** While the legislative framework to support equality of access to all services is in place, there is clearly much to be done for black and minority ethnic groups and newly arrived communities to be fully included. The National Directors, working with the Valuing People regional team, and Deputy Regional Directors for Social Care and Partnerships will lead a programme of work:
- to raise the profile of this issue and ensure it is taken seriously by all agencies supporting people with learning disabilities and their families so that locally they will design and commission services to ensure genuine inclusion; and
 - including working with the National Advisory Group for People with Learning Disabilities and Ethnicity (NAGLDE) to develop and disseminate good practice to inform policy, in line with NAGLDE’s recommendations.

People with autistic spectrum conditions

- 1.14** People with learning disabilities and autistic spectrum conditions need support that responds to their individual needs, from staff with understanding and experience of working with them. In designing and delivering local services which will address the specific needs of

43 *Valuing People: second national ethnicity survey*, Chris Hatton (2006/07): <http://valuingpeople.gov.uk/dynamic/valuingpeople90.jsp>

44 *People from minority ethnic backgrounds living in rural areas*, Ghazala Mir, Centre for Research in Primary Care, University of Leeds: www.valuingpeople.gov.uk/echo/filedownload.jsp?action=dFile&key=459-

people with learning disabilities and autistic spectrum conditions, health and social care bodies may wish to consult the DH note *Better Services for People with an Autistic Spectrum Disorder: A Note Clarifying Government Policy and Describing Good Practice*.⁴⁵ With other government departments, DH is working to develop a strategy on support for adults with autistic spectrum conditions, including commissioning prevalence research.

Learning disabled offenders in custody and the community

1.15 A growing number of people with learning disabilities appear to be in contact with the criminal justice system. Some people with mild learning disabilities are in prison. Often their specific needs are not recognised or met because their learning disability is not visible. Commitment was made in the Youth Crime Action Plan to consider how Government best meets young offenders' special educational needs as part of the new funding and delivery model and plans should be developed in the context of the evidence and recommendations from the Bercow Review of Services for Children with Speech, Language and Communication Needs.⁴⁶ Person centred planning and health action planning are particularly important for people who are in prison or subject to community sentences. As part of offender management processes there should be a health screening programme that identifies an offender's learning disability and any physical and/or mental health issues. This should form the start of the individual's health action plan and enable access to appropriate education and rehabilitative programmes. Good practice guidance, issued in 2007, is now available for people working in the criminal justice system on how to work with and support people with learning disabilities.⁴⁷

45 *Better Services for People with an Autistic Spectrum Disorder: A Note Clarifying Current Government Policy and Describing Good Practice*: www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_065242

46 *Better Communication: An Action Plan to improve services for children and young people with speech, language and communication needs*. Department for Children, Schools and Families, DCSF – 01062 (2008)

47 *Positive Practice Positive Outcomes: A Handbook for Professionals in the Criminal Justice System working with Offenders with Learning Disabilities*, Care Services Improvement Partnership (2007): www.kc.csiip.org.uk/viewresource.php?action=viewdocument&doc=98519&grp=1

Learning disability awareness training for prison staff

In 2007 a new one-day training course was piloted across the south-east region. The course was open to all types of staff working in a prison setting in the region. It is delivered by a learning disability specialist and a co-trainer with a learning disability and also includes DVD footage of ex-offenders with learning disabilities talking about their experiences.

It is designed to raise awareness of the needs of individuals in prison with learning disabilities and related conditions. It covers identification of learning disabled behaviour, the physical and mental health needs of people with learning disabilities, communication and a variety of issues specific to managing people with learning disabilities within the unique environment of the prison system.

The pilot was a success and now has additional funding to cover work across England and Wales, with all prisons being invited to send three key members of staff to attend and hopefully share all they have learned upon returning.

The organisations who have developed and run this work are KeyRing and the Skillnet Group, working with Valuing People and the Care Services Improvement Partnership in the south-east region.

Children with learning disabilities

1.16 Since *Valuing People* there have been a number of key policies on services for children – not least the £340 million *Aiming High for Disabled Children* programme for local authority children's services in the period 2008–11. It has three priority areas – access and empowerment, responsive services and timely support, and improving quality and capacity. The funding includes £280 million for increasing short-breaks for disabled children, £35 million for a childcare accessibility project to improve access to childcare for disabled children, £19 million for a Transition Support Programme and £5 million for developing parents' forums in every local authority area. PCTs have also received additional funding which is included in their baseline allocations.

- 1.17** However, while these policies have started to address the particular issues and imbalances that children with learning disabilities face, there is still work to be done. Some of the obstacles that young people in transition and adults face are rooted in their own lack of expectation and aspiration about their adult lives, often as a result of negative messages from those around them or simply a lack of understanding.
- 1.18** For this reason, there has been much work to ensure that some of the headline strands of work (around employment, for example) take account of the need to engage those involved in pre-16 education policy, as well as health and social care delivery, recognising that these issues need to be addressed in childhood and partly through the compulsory education sector. Social care and healthcare professionals and teachers all have a role to play in raising the expectations of children and young people (and their families) about the kind of lives they can live as adults. Families and parents are vital in this too, and their own fears about the support available to ensure their sons or daughters can grow up into fully-fledged adult citizens need to be taken seriously and addressed.

Family carers and families

- 1.19** Families are usually the main source of love, care and support for children and adults with learning disabilities. This is especially the case



for people with complex needs. Even when people leave home, they do not leave the family. Families continue to offer a lifetime of involvement, support and advocacy. Sometimes family members can disagree. When this is the case it is important that everyone's views and perspectives are understood and respected. Where there is clear and continued disagreement between people with learning disabilities and their families, they may need support to resolve their differences of opinion, including independent advocacy to support the person with a learning disability.

Kieran's story

Kieran is a 39-year-old man with severe learning disabilities. He lives at home with his mum and dad. Kieran used to go to a respite centre for a few weeks each year but his parents didn't get any choice about when that was. Things became difficult with the respite service: Kieran always seemed poorly whenever his parents went away or they would get telephone calls to ask them to go in – so it was no respite. Kieran's social worker told them about Direct Payments and they decided to use it to employ carers to come to the house to support Kieran while they were away.

They now have two carers and four bank carers for emergencies. Kieran is much happier and his parents feel so much more settled about going away. Recently they went on a cruise and were able to relax and enjoy themselves without worrying about Kieran. Kieran's parents say: 'We are so happy – we wouldn't change a thing. Our plan for the future is for Kieran to remain living in his own home with support, and for us to move out when we retire. We never thought this could happen but now it can.'⁴⁸

CASE STUDY

48 Taken from *Self-Directed Support, People's Stories, and Volume One*, part of a collection of stories put together by the Self-Directed Support team in Barnsley

1.20 It is vital that family carers are recognised and valued as key partners in the delivery of this strategy. Yet many family carers still face difficulties and further action is needed to address these:

- families from ethnic minorities are at greater risk of isolation;
- over 29,000 adults live with a parent over the age of 70 (Mencap estimate).⁴⁹ CSCI found many local authorities were failing to plan for the future with older families;⁵⁰
- people with learning disabilities who are carers are often invisible to services because of lack of recognition of mutual caring of parents or partners;
- *Healthcare for All* said family carers were not valued as partners by health service professionals, with serious consequences for their family member;
- many family carers are unaware of their right to a carers' assessment or are turning them down because they do not think it will lead to getting the support they need.

1.21 The Government published *Carers at the heart of 21st-century families and communities* in June 2008. This ten-year, cross-government strategy says that all family carers should get support in their **own** right to enable them to live a life beyond their caring role and responsibilities. The strategy is underpinned by five key aspirations that by 2018:

- carers will be respected as expert care partners and will have access to the integrated and personalised services they need to support them in their caring role;
- carers will be able to have a life of their own alongside their caring role;
- carers will be supported so that they are not forced into financial hardship by their caring role;
- carers will be supported to stay mentally and physically well and treated with dignity; and
- children and young people will be protected from inappropriate caring and have the support they need to learn, develop and thrive.

49 The Housing Timebomb: the housing crisis facing people with a learning disability and their elderly parents, Mencap (2008): www.mencap.org.uk/document.asp?id=293&andGroup=&subjectid=&sorter=1&origin=pageType&pageType=112&pageno=&searchPhrase=

50 *The State of Social Care in England*, CSCI (2005/06)

- 1.22** The Government has made £255 million available between 2008 and 2011, to help implement the strategy. This is on top of the £720 million already committed between 2008 and 2011 in the Carer's Grant.
- 1.23** The Standing Commission for Carers has been charged with ensuring that **all** family carers are included in implementation of the new National Carers Strategy.

Making it happen locally and regionally – key recommended actions

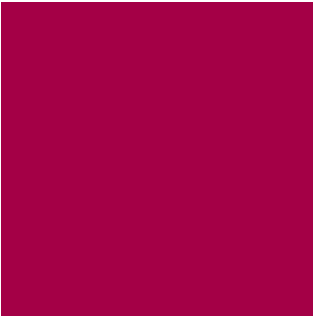
- Commissioners and service providers to address the recommendations of the Mansell Report and to include people with complex needs in the development of self-directed services in their area.
- Partnership boards to develop their own Equalities Schemes to show how they are implementing and monitoring equalities legislation.
- Local authorities to carry out a Carers' Assessment when there are planned changes to the support for a person with learning disabilities who is being supported by their family in some way.
- Deputy Regional Directors for Social Care and Partnerships to work within the Government Offices and with Valuing People and personalisation regional leads to build capacity and capability so that local planners and service deliverers will:
 - include and take account of the issues for people from the four excluded groups;
 - ensure their practice is in line with national policy, law and good practice; and
 - ensure that they and partnership boards are aware of the new opportunities for family carers.

National level actions for government

- The National Directors will appoint national programme leads to champion issues for people with more complex needs and people from black and minority ethnic groups and newly arrived communities and support, through Deputy Regional Directors for Social Care and Partnerships, regional and local work programmes to bring about service improvements to address the needs of these groups.

- The National Directors will also appoint a national programme lead for families who will lead a programme of work including:
 - continued investment in the National Valuing Families Forum;
 - investment in carer organisations to build their capacity to deliver for family carers of people with learning disabilities, and carers who have a disability; and
 - funding a national Partners in Policy Making⁵¹ course to bring family carers and disabled people together to help build their capacity as leaders.
- The National Directors will lead work to explore how to introduce carers' impact assessments on all new government policies relevant to family carers.
- DH will ensure that the needs of offenders with learning disabilities are included in the delivery programme around offender health.
- The forthcoming good practice guidance for commissioners of forensic services for people with learning disabilities will help ensure that local commissioning reflects the needs of offenders with learning disabilities both in prison and on release into the community. DH will consider how it monitors implementation of the guidance.

Chapter 2: Personalisation – starting with the individual and their family



Overall policy objective: All people with learning disabilities and their families will have greater choice and control over their lives and have support to develop person centred plans.

Joe

'Self directed support has enabled us to be an ordinary family again. Joe has started to live a life that is comparative with his peers, if not in some instances he is in a far better position. He now has his own personal assistants who assist him to do ordinary things like go to college, support him with his micro-enterprise, go to the gym, have a bath, and eat his meals. He has his own car which enables him to get out and about and more recently he has bought his own home next door to us. In fact, using the concept of Joe having his own individual budget has enabled him to design his support in a way that makes sense to him. He hasn't taken any more money from the State, he has just utilised it in a far better way.' Caroline Tomlinson, Joe's mum⁵²

CASE STUDY

2.1 Person centred planning, advocacy and Direct Payments to give people more choice and control in their lives were at the heart of the original Valuing People. When done properly, person centred approaches, support planning and personal budgets can make a significant difference in people's lives. But their impact has so far been limited to relatively few people:

- Direct Payments are only 1.1% of total expenditure on learning disability services;
- a lot of people still do not have a person centred plan; and
- little work has been done on involving people with complex needs in their own planning through the creative use of different types of communication.

InControl

*'InControl is one of the most promising approaches to self-directed services. Building on years of work by disabled people to control the support they get, InControl began as a partnership between the Department of Health's Valuing People Support Team, Mencap, a group of local authorities and independent development organisations working in the field of disability. They came together in 2003 to help local authority social services departments adopt 'self-directed support' systems for social care in which disabled people would control how they live and the support they need. In 2003 six local authorities – Essex, Gateshead, Redcar and Cleveland, South Gloucestershire, West Sussex and Wigan – piloted InControl's self-directed support model focusing on people with learning difficulties. The InControl model quickly spread from people with learning and physical disabilities to older people who make up most of those receiving social care. By November 2007, 107 local authorities were members of InControl, and 2,300 people were receiving personal budgets using its model, many of them elderly people.'*⁵³

'Reforming social care to achieve personalisation for all will require a huge cultural, transformational and transactional change in all parts of the system, not just social care but also for services across the whole of local government and the wider public sector.'

*Transforming Social Care, LAC, DH 2008*⁵⁴

- 2.2** *Putting People First* makes an explicit commitment to transform services, and make them more personalised to the needs of the individual user. It identifies the need to empower citizens to participate in their communities as well as shape their own lives and the support they receive.
- 2.3** *Putting People First* sets out a vision for transforming social care, supporting local authorities and social care partners to reshape and

⁵³ *Making It Personal*, Charles Leadbeater, Jamie Bartlett, Niamh Gallagher, Demos (2008)

⁵⁴ www.dh.gov.uk/en/publicationsandstatistics/lettersandcirculars/localauthoritycirculars/DH_081934

redesign their systems to give people more control over their support and allow them to use the resources available more flexibly. Greater personalisation means:

- commissioners changing how they work and what they decide to buy, and getting better at listening to people;
- providers working differently, in particular by setting up new types of services around individuals rather than groups;
- commissioners and providers working with local user-led organisations to understand what support people want;
- more individuals and families commissioning their own services;
- a competent and well-trained workforce who are flexible, person centred and skilled in supporting people to be fully included in society;
- person centred planning and support planning;
- people who inspect and check services using new ways of making sure services are personalised and meet people's wants and needs;
- more consideration being given to responding to people's cultural and religious beliefs;
- support for advocacy, including peer and self-advocacy, and working with user-led organisations;



- more focus on assistive technology to support people in their daily lives;
- continued effort to enable everyone to live independent lives in their local communities – this includes people with more complex needs; and
- market development to ensure there is a range of options for individuals to choose from.

2.4 Greater coordination between health and social care services and a greater focus on outcomes rather than services should mean that people with learning disabilities and their families can expect a more person centred approach to planning support and improved outcomes in terms of social inclusion, empowerment and equality. More people with learning disabilities should be able to commission their own services to live independently and have real choice about the way they live their lives.

Paul's story

Paul really wanted a girlfriend to go out with and 'do new things and have nice meals with friends like my brother does'. At his person centred review he told people he could not get a girlfriend because he could not go out on his own. Paul talked about Joan who was a woman he loved to spend time with at the Gateway Club. One of the actions from his person centred review was that Paul would work with his key worker, Sam at the group home, to develop Paul's relationship circle and think about his community connections. Paul and Sam used the relationship circle to think about who the important people were in his life, and this led to actions to support Joan and Paul to meet at other times as well as at the Gateway Club. As a result of this review Paul now has a girlfriend and Paul and Sam are now members of the local drama group. Paul said: 'Dating Joan is the best thing that ever happened to me, all 'cos of my review.'

CASE STUDY

- 2.5** The evaluation report of the individual budget pilot programme published in October 2008⁵⁵ found that holding an individual budget was associated with better overall social care outcomes and higher perceived levels of control. Building on the learning derived from the individual budget pilots, the recent Green Paper on welfare reform announced public consultation on the potential of a right to control individual budgets across different income streams for disabled people. The Health and Social Care Act 2008 extends the benefits of direct payments to currently excluded groups. Lord Darzi's Next Stage Review of the NHS sets out the intention to explore using personal health budgets within the health service.
- 2.6** Within the context of the transformation and personalisation agenda it is important that the issues specific to people with learning disabilities and their families are properly addressed. This is particularly the case for those with more complex needs and from black and minority ethnic and newly arrived communities.

Making it happen locally and regionally – key recommended actions

- Local authorities and their partners to build capacity around person centred approaches and planning so that all people with learning disabilities and their families have support to develop plans which identify what is important to them now and in the future, and support and services that are informed by their person centred plan.
- Partnership boards to review their person centred planning strategies in light of the forthcoming person centred planning guidance.
- Partnership boards to work with key agencies to ensure that personalisation strategies include person centred planning approaches.
- Personalisation strategies to include implementation of person centred planning, support planning and carers' impact assessments for all adults with complex needs or where changes are planned in their support and services.
- Services to have person centred plans for everyone they support, and to use these to review and improve the support they provide to individuals to ensure that agreed outcomes continue to be met.

55 *Evaluation of the Individual Budgets Pilot Programme: Final Report (2008)*: www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_089505



- A greater focus on universal services and the use of community resources to help support people to live within their local community, whether or not they are eligible for social care funding.
- Local authorities to ensure that there are user-led organisations in their area which make sure support is available for people with learning disabilities and their families.
- DH has made over half a billion pounds available to local authorities to support local transformation of social care through the new Social Care Reform Grant. The grant is worth £85 million in 2008/09, £195 million in 2009/10 and £240 million in 2010/11. Deputy Regional Directors for Social Care and Partnerships will – with regional personalisation and Valuing People regional leads – ensure that personalisation is prioritised within the newly funded delivery support programmes and that people with learning disabilities and their families benefit. This will include involving people and their families in the development of local strategies.

National level actions for government departments

- The National Directors will work with relevant government departments and Deputy Regional Directors for Social Care and Partnerships to ensure that the reform set out in *Putting People First* includes and benefits all people with learning disabilities and their families.

- DH is working with key stakeholders (including the Association of Directors of Adult Social Services (ADASS), the Local Government Association (LGA) and the Improvement and Development Agency (IDeA)) to develop a programme to drive and support the necessary changes.
- DH will publish new person centred planning guidance and ensure this is disseminated throughout the regions.
- The Office of the National Director (in partnership with the *Putting People First* team) will explore how person centred information can be used to inform strategic commissioning and will disseminate good practice throughout the regions.

Chapter 3: Having a life



I. Better health

Overall policy objective: All people with learning disabilities get the healthcare and the support they need to live healthy lives.

'Everyone can expect to live healthy lives with the appropriate support from a personalised and fair National Health Service, that ensures the most effective treatments within a safe system.'

High Quality Care For All (2008)

'I get taken to this big place and I don't know what will happen, doctors use lots of big words, I get scared, it's important to know what to eat.'

'I may not be able to tell you that I'm poorly.'

Feedback provided as part of the Valuing People Now Consultation (2008)

- 3.1** Good health begins with promoting well-being and preventing ill-health and this is the same for people with learning disabilities; healthy active lifestyles have to be the starting point for all. Access to the full range of healthcare services including dentistry, screening, sexual health, maternity, health visiting and end-of-life care is essential in ensuring that people with learning disabilities can take greater control of their health and well-being.

Everybody Active

Everybody Active in Reading, a sport and physical activity programme for adults with learning disabilities, was developed to enhance well-being. The programme delivers weekly sessions including boccia, football, swimming, gym, trampolining, walking and cycling. There are also one-off events throughout the year to celebrate regular participants' achievements and commitment. In 2007–08 the programme engaged 577 participants in community-based activities. Everybody Active has a Pathway Exercise Referral scheme whereby GPs and other healthcare professionals can refer suitable patients to leisure facilities for fitness evaluations and exercise programmes.

The Everybody Active programme aims to increase physical activity in order to benefit the health of adults with learning disabilities.

3.2 However, most people with learning disabilities have poorer health than the rest of the population and are more likely to die at a younger age. There is clear evidence that their access to the NHS is often poor and characterised by problems that undermine personalisation, dignity and safety. At worst, reports have identified abuse, undiagnosed illness and, in some cases, avoidable death.

3.3 Key issues for the NHS are:

- achieving full inclusion of people with learning disabilities in its mainstream work on reducing health inequalities; and
- ensuring high-quality evidence-based specialist health services.

3.4 The overarching policy relating to the health of all people is covered in the final report of the NHS Next Stage Review.

*'The vision this report sets out is of an NHS that gives patients and the public more information and choice, works in partnership and has quality of care at its heart – quality defined as clinically effective, personal and safe. It will see the NHS deliver high quality care for all users of services in all aspects, not just some.'*⁵⁶

The forthcoming Child Health Strategy will be framed around the government's vision for children and young people's health and well-being for 2020 and will articulate the work to deliver this.

3.5 A number of reports in recent years have highlighted the low priority and focus given to health and healthcare for people with learning disabilities:

- *Equal Treatment: Closing the Gap*⁵⁷ highlighted failings in access to healthcare and providing appropriate treatment for people with learning disabilities.
- *Death by Indifference*⁵⁸ described the circumstances surrounding the deaths of six people with learning disabilities while they were in the care of the NHS.

56 *High Quality Care for All: NHS Next Stage Review Final Report*
www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_085825

57 *Equal Treatment: Closing the Gap*, Disability Rights Commission (2006)

58 *Death by Indifference*, Mencap (2007)

- *A life like no other*⁵⁹ found that adults with learning disabilities are particularly vulnerable to breaches of their human rights in healthcare.

3.6 In 2007, DH published a wide-ranging action plan, *Promoting Equality*,⁶⁰ to respond to the recommendations of the Disability Rights Commission report, with a particular focus on:

- promoting the implementation of annual health checks, supported by a framework to help PCTs commission enhanced primary care services for people with learning disabilities, including health action plans and strategic health facilitators;
- PCT commissioning: identifying and spreading best practice in commissioning services that meet the needs of people with learning disabilities, as part of the wider World Class Commissioning programme;
- education and training: working with regulatory and education bodies to address learning disability issues as part of training for healthcare professionals;
- information and information systems: ensuring that learning disability is reflected in the minimum dataset for Joint Strategic Needs Assessments and in wider work to improve equality monitoring across NHS services;
- equality assessment of new DH and NHS policies; and
- ensuring equitable access to and uptake of screening programmes.

3.7 The NHS Operating Framework 2008/09 required SHAs, PCTs and provider trusts to pursue service improvements and deliver action plans on remedying shortcomings in learning disability services. Most regions are now using a self-assessment and performance framework to help identify priorities and to develop regional and local action plans to improve local health services.⁶¹

59 *A life like no other*: a national audit of specialist inpatient healthcare services for people with learning difficulties in England, Healthcare Commission (2007)

60 *Promoting equality: Response from Department of Health to the Disability Rights Commission Report, 'Equal Treatment: Closing the Gap'*, Department of Health (2007)

61 See text box on page 127

Primary and acute healthcare

'Martin, aged 43, went without food for 26 days whilst he was in hospital following a stroke. By the time staff realised what was happening, he was too weak to be helped. Martin died on 21 December 2005. He had severe learning disabilities and no speech.'

Martin's family told his story as one of six cases highlighted within Mencap's *Death by Indifference* report (2006)

It should be noted that the circumstances and complaints made by the families are still subject to judgement by the Ombudsman.

- 3.8** In response to *Death by Indifference*, the then Secretary of State for Health invited Sir Jonathan Michael to head an Independent Inquiry into access to healthcare for people with learning disabilities. The report of that Inquiry – *Healthcare for All* – was published in July 2008. The ten main recommendations of that report, and the Department's responses are below. The NHS Chief Executive has already written to chief executives of SHAs, PCTs and provider NHS trusts to ask them to satisfy themselves that reasonable adjustments are being made. This strategy provides the opportunity to draw together into a single programme the action that the Government will take to address the Independent Inquiry recommendations, building on the existing Promoting Equality work programme.



Healthcare for All – the independent inquiry into access to healthcare for people with learning disabilities by Sir Jonathan Michael (2008)⁶²

Leadership is essential to deliver policy effectively for vulnerable groups of society. People with learning disabilities are amongst the most vulnerable and many have some of the greatest health needs. Together, the evidence implies that ‘reasonable adjustment’ is needed to policy on devolution of decision making on healthcare to local level for people with learning disabilities. Current policy is failing this vulnerable group.

Response: We acknowledge the role DH has to play in making this a priority for leaders across the NHS. This response to the Inquiry forms an integral part of *Valuing People Now* and will continue to be a key element of the delivery plan. That delivery will be led by the new National Directors for Learning Disabilities and overseen by the Director of Social Care, Local Government and Care Partnerships and the Minister for Care Services, who jointly chair the Learning Disability Programme Board.

The work on the detailed response to the Inquiry will be led by a cross-departmental group, chaired by the Director of Primary Care and with representation from the Equality and Human Rights Commission. This group will be responsible for overseeing delivery of commitments around mainstream (non-specialist) healthcare for people with learning disabilities, reporting regularly to the Programme Board.

62 *Healthcare for All: report of the independent inquiry into access to healthcare for people with learning disabilities*, Sir Jonathan Michael, Department of Health (2008)

RECOMMENDATION 1

Those with responsibility for the provision and regulation of undergraduate and postgraduate clinical training must ensure that curricula include mandatory training in learning disabilities. It should be competence-based and involve people with learning disabilities and their carers in providing training.

Response: We accept this recommendation. We are working through education commissioners and education providers to review and improve training provided for healthcare staff, in line with best practice, to address the needs of people with learning disabilities. We will encourage the engagement of service users and carers in the design and delivery of this training. We will expect SHAs to account to us at the year-end to give appropriate assurances that this is being taken forward.

We will also continue working with the professional regulatory bodies, who are responsible for setting educational standards for the health and social care professions, to agree what further steps we can each take to support improvements in training.

RECOMMENDATION 2

All healthcare organisations, including the Department of Health, should ensure that they collect the data and information necessary to allow people with learning disability to be identified by the health service and their pathways of care tracked.

Response: We accept this recommendation. The DH Permanent Secretary chairs a group responsible for ensuring improvements in the data, information and information systems used by the NHS to monitor equality of access to health services and equality of health outcomes. Building on this work, we will ask the NHS Information Centre to work with the Public Health Observatory for learning disability (see below) to identify the practical changes needed to:

- ensure more systematic recording of learning disability within general practice. This will be helped significantly by the new Directed Enhanced Service for annual health checks, which will help GP practices ensure that the registers they maintain under the Quality and Outcomes Framework reflect information from local authority registers of people with learning disabilities known to services;
- develop more consistent systems to ensure that information is shared with other healthcare providers when GP practices make referrals to other services – supported by the review of disability definitions currently being undertaken by the Office of National Statistics; and
- allow appropriate data from GP practice systems to be compared with data from other NHS sources (eg the Secondary Uses Service) to allow better analysis of the uptake of healthcare interventions and health outcomes in relation to people with learning disabilities.

RECOMMENDATION 3

Family and other carers should be involved as a matter of course as partners in the provision of treatment and care, unless good reason is given, and Trust Boards should ensure that reasonable adjustments are made to enable and support carers to do this effectively. This will include the provision of information, but may also involve practical support and service co-ordination.

Response: We accept this recommendation. *Valuing People Now* recognises the important role that carers play and the importance of working in partnership with them in the provision of treatment and care. The Government's National Carers Strategy, published in June 2008, sets out how carers should be included as partners in care. The strategy includes a commitment to issue information prescriptions to carers and to enable carers to receive other appropriate information, especially in cases where mental capacity is an issue.

The National Carers Strategy also recognises how the additional stress of caring roles may affect the carer's own health. It proposes piloting annual health checks for family carers and ensuring regular access to short break services and support.



RECOMMENDATION 4

Primary care trusts should identify and assess the needs of people with learning disabilities and their carers as part of their Joint Strategic Needs Assessment. They should consult with their Local Strategic Partnership, their Learning Disability Partnership Boards and relevant voluntary user-led learning disability organisations and use the information to inform the development of Local Area Agreements.

Response: We accept this recommendation. As part of the World Class Commissioning programme, we are working with PCTs to help identify and spread best practice in commissioning services to meet the needs of people with learning disabilities, including best practice in needs assessment and in engagement with service users, families and carers, and partnership boards. This should form part of the Joint Strategic Needs Assessments undertaken with local authorities and other community partners.

Good commissioning includes working in partnership with healthcare providers, for instance through systems of strategic health facilitation and acute liaison, to help ensure that people with learning disabilities receive timely, convenient access to the full range of services needed to meet their health needs and that they receive high-quality, personalised and joined-up care across primary care, community health services and hospital settings. It also includes reviewing workforce requirements relating to primary healthcare facilitation and acute hospital liaison to help ensure that reasonable adjustments are made.

The minimum dataset for Joint Strategic Needs Assessments, which the Inquiry commended, includes indicators on the number of people with learning disabilities resident in each area, the number in employment and the number in settled accommodation. The minimum dataset also includes an indicator on carers' assessments. The number of annual health checks for people with learning disabilities known to local authorities will also now be collected as part of the NHS Vital Sign indicators.

DH recommends the core dataset as a starting point for Joint Strategic Needs Assessments. We encourage PCTs and local authorities to work with service users and their families and carers to identify additional information that can inform the assessment.

RECOMMENDATION 5

The Department of Health should raise awareness in the health service of the risk of premature avoidable death; and to promote sustainable good practice in local assessment, management and evaluation of services, the Department of Health should establish a learning disabilities Public Health Observatory. This should be supplemented by a time-limited Confidential Inquiry into premature deaths in people with learning difficulties to provide evidence for clinical and professional staff of the extent of the problem and guidance on prevention.

Response: We accept this recommendation. We agree that PCTs, as commissioners of health services, would benefit from better support in assessing the needs of people with learning disabilities in their local population, in assessing how far these needs are currently being met through the services available, and in understanding comparative health outcomes for people with learning disabilities.

We agree that a Public Health Observatory would help PCTs embed best practice in these areas. We will commission this programme of work either from a stand-alone Public Health Observatory or from one of the existing Public Health Observatories.

We agree that a time-limited Confidential Inquiry into premature deaths in people with learning disabilities would help improve the clinical evidence base that should underpin commissioning of local services. We are developing a specification for the Inquiry and propose inviting proposals from potential organisations.

RECOMMENDATION 6

The Department of Health should immediately amend Core Standards for Better Health, to include an explicit reference to the requirement to make 'reasonable adjustments' to the provision and delivery of services for vulnerable groups, in accordance with the disability equality legislation. The framework that is planned to replace these core standards in 2010 should also include a specific reference to this requirement.

Response: We accept the aim of this recommendation. As public bodies, NHS organisations are required by the Disability Discrimination Act 1995 to make reasonable adjustments to the provision and delivery of their services to vulnerable groups.

Core Standards for Better Health will no longer be used as the basis for performance assessment of healthcare services once the Care Quality Commission takes over the role of the Healthcare Commission from April 2009. However, the Healthcare Commission is already working jointly with the Commission for Social Care Inspection and the Mental Health Act Commission, with a specific focus on making sure that the commissioning and provision of services for people with learning disabilities meet the provisions of disability discrimination and other relevant legislation, including the Human Rights Act 1998.

We have included specific provision in the Health and Social Care Act 2008 to make sure the Care Quality Commission is able to take account of all other relevant legislation, including the Disability Discrimination Act 1995.

Earlier this year, the Department consulted on a high-level framework for the requirements against which providers should be assessed from 2010/11 onwards. In doing so, we have been particularly mindful of the needs of vulnerable groups. Our proposals included requirements that providers safeguard people when they are vulnerable and that they assess, plan and deliver care in a way that reflects people's individual needs and diversity. We are currently analysing and considering the responses to the consultation and will publish the Government's response shortly. Once the high-level requirements are set in regulations, the Care Quality Commission will develop and consult on the criteria that it will use to assess compliance with regulations.

The Care Quality Commission has made it clear that protecting the rights of people who use services, particularly the most vulnerable, will be one of its key priorities. We are therefore confident that it will ensure that the criteria it develops will take account of the requirements of the Disability Discrimination Act 1995.

RECOMMENDATION 7

Inspectors and regulators of the health service should develop and extend their monitoring of the standard of general health services provided for people with learning disabilities, in both the hospital sector and in the community where primary care providers are located. The aim is to support appropriate, reasonable adjustments to general health services for adults with learning disabilities and their families and to ensure compliance with and enforcement of all aspects of the Disability Discrimination Act. Healthcare regulators and inspectors (and the Care Quality Commission, once established) should strengthen their work in partnership with each other and with the Commission for Equality and Human Rights, the National Patient Safety Agency and Office for Disability Issues.

Response: We accept this recommendation. To strengthen assurance of equality throughout the health and social care system, DH will, from April 2009, be requiring Accountable Officers of NHS organisations and Arm's Length Bodies to provide assurance that their organisation is complying with equalities legislation through annual statements of internal control. Statements of internal control are published as part of each organisation's audited annual accounts.

We will work with the new Care Quality Commission to help it to take forward the lessons learned from the current regulators' work and to support the partnership approach set out in this recommendation.

In addition, we welcome the commitment of the Equality and Human Rights Commission to work with the regulatory agencies to ensure a coordinated approach to delivering change.

RECOMMENDATION 8

The Department of Health should direct primary care trusts (PCTs) to secure general health services that make reasonable adjustments for people with learning disabilities through a Directed Enhanced Service. In particular, the Department should direct PCTs to commission enhanced primary care services which include regular health checks provided by GP practices and improve data, communication and cross-boundary partnership working. This should include liaison staff who work with primary care services to improve the overall quality of healthcare for people with learning disabilities across the spectrum of care.

Response: We accept this recommendation. DH has recently reached agreement with the British Medical Association (BMA) to introduce a Directed Enhanced Service for annual health checks for people with learning disabilities known to local authorities. This means that all PCTs in England are under a direction to commission annual health checks from GP practices in their area and to arrange appropriate training for GPs and GP practice staff. These arrangements will initially run until 31 March 2010. The number of people with learning disabilities known to local authorities who receive annual health checks will be a new Vital Signs indicator. Over the next year, we will work with groups representing patients, families and carers and professional groups to review the effectiveness of these arrangements and consider improvements for the future.

GPs and GP practice staff will receive training in meeting the needs of people with a learning disability provided by Strategic Health Facilitators or local Community Learning Disability Team staff in partnership with self-advocates and family carers. We are also promoting the development of Practitioners with a Special Interest in learning disability. This will be focused initially on GPs and pharmacists but we hope it will expand to include other professionals, who can then serve as a resource to other health practitioners in their area.

Through the recent NHS Operating Framework for 2009/10, we have reinforced the importance of securing general health services that make reasonable adjustments for people with learning disabilities and the need for PCTs to have arrangements in place for communication and partnership working to improve the overall quality of healthcare for people with learning disabilities. We will work with SHAs to review the progress of PCTs in making improvements in these areas.

RECOMMENDATION 9

Section 242 of the National Health Service Act 2006 requires NHS bodies to involve and consult patients and the public in the planning and development of services, and in decisions affecting the operation of services. All Trust Boards should ensure that the views and interests of people with learning disabilities and their carers are included.

Response: We accept this recommendation. The Operating Framework for 2008/09 set out the importance of close partnership working between PCTs and local authorities, with a particular focus on person centred health plans for people with learning disabilities. *Valuing People Now* recommended that PCTs should be represented on partnership boards. The strengthened role of partnership boards should give PCTs access to the views of service users and families and carers, to help PCTs to assess needs and review services and commissioning improvements in health and healthcare.

The establishment of Local Involvement Networks (LINKs) in April 2008 provides a key mechanism to improve the commissioning of services for people with learning disabilities. LINKs provide communities with the opportunity to influence health and social care services – including disability services – and give citizens the chance to have their say in a much wider range of ways.

RECOMMENDATION 10

All Trust Boards should demonstrate in routine public reports that they have effective systems in place to deliver effective, ‘reasonably adjusted’ health services. This should include arrangements to provide advocacy for all those who need it and arrangements to secure effective representation on PALS [Patient Advice and Liaison Services] from all client groups including people with learning disabilities.

Response: We accept this recommendation. It is good practice for Trusts to show explicitly how they have adapted their services to make them accessible to people with disabilities. In addition, it is good practice for Trusts to include family carers and people with learning disabilities as equal partners with expertise, who can support these organisations in achieving this objective.

3.9 At a national level, there will also be work to ensure that the NHS fully respects the human rights of people with learning disabilities, including the first NHS Constitution setting out the rights and responsibilities of all individuals in relation to the NHS.

3.10 DH is running a ‘Human Rights in Healthcare’ project. One of the pilot sites is the Learning Disabilities Directorate in Mersey Care NHS Trust. This site has produced materials including:

- a human rights questionnaire for in-patients;
- a human rights based risk assessment;
- a human rights benchmarking tool;
- a human rights risk management tool for PCTs and Trusts in relation to people with more complex needs; and
- a Trust-wide human rights strategy.⁶³

⁶³ Details of the Mersey Care pilot materials and other resources on human rights in healthcare can be found at: www.dh.gov.uk/en/Managingyourorganisation/Equalityandhumanrights/Humanrights/DH_088783

Example of good practice

In Staffordshire and Stoke-on-Trent, PCTs have invested in eight Primary Healthcare Facilitators, providing on average one post holder per 150,000 general population. All are learning disability nurses and are employed within the PCTs to work with GP practices to provide support, training and tailor-made resources for primary care staff to enhance their capacity and abilities to provide good quality healthcare to people with learning disabilities.

*'For a person with a learning disability who finds it hard to communicate or struggles to understand things, it is really important that staff **take time** to listen to them, hear their views, explain things slowly and do simple things like cut up their food or feed them if necessary.'*

Nicola Smith, former Co-National Director for Learning Disabilities,
taken from an article in *Learning Disability Today*



3.11 Good commissioning needs to address the quality of healthcare and support provided across all healthcare settings. As highlighted in *Death by Indifference* and *Healthcare for All*, there are particular needs within acute general hospitals to ensure the effectiveness of care pathways and communication. Acute hospital liaison staff can help to ensure that reasonable adjustments are identified, that systems of support are agreed and that hospital staff receive training to improve the quality of healthcare that people with learning disabilities receive in general hospitals.

Learning disability acute hospital liaison nurses

At the Royal Sussex Hospital in Brighton, the learning disability acute hospital liaison nurses are working both within the hospital and in people's homes. Prior to admission, they help with the preparation and planning for hospital by using hospital books and communication aids, and by liaising with families. In the hospital, they coordinate the care pathway through admission and treatment; they will also work with the discharge team to ensure appropriate support is in place and will offer follow-up visits in the community to help individuals and their families to understand new health needs or future treatment.

The nurses also manage small caseloads to prevent re-admission of individuals with chronic illnesses.

CASE STUDY

Specialist and mental health services

3.12 A small but significant number of people with a learning disability will require specialist support and treatment from the NHS, provided by specialist learning disability services or mental health services. People with a learning disability are more likely to suffer from mental ill-health than the general population. However, we know from the Healthcare Commission audit of specialist services that people do not always get the appropriate assessment and treatment they require delivered in the right place; and too often people can be sent to expensive out of area

placements. In many places, people with learning disabilities are unable to access mainstream mental health services, and there is often poor communication and partnership working between specialist learning disability services and mental health services.

- 3.13** Some people with learning disabilities and additional complex or profound physical disabilities will require health professionals from mainstream and specialist learning disability services to work in partnership in order to use medical technology and to access essential therapeutic assessments and interventions from nurses, physiotherapists, psychiatrists, psychologists, occupational therapists, speech therapists and dieticians. Similar partnership arrangements are also needed to ensure that people with more complex needs gain access to the best care and treatment in the full range of health services, from maternity services through to end of life care.
- 3.14** The NHS will retain the funding required to run appropriate specialist health services. The nature and size of these services will need to be agreed between the PCT and local authority. Good practice guidance on commissioning specialist adult learning disability health services was issued in 2007.⁶⁴
- 3.15** People with learning disabilities are entitled to the support they require to access mainstream mental health services as set out in the National Service Framework (NSF). This NSF is for all people with mental health needs of working age, including people with a learning disability.⁶⁵ Following the independent review of Children and Mental Health Services, a National Advisory Council for children's mental health and psychological well-being has been developed. In addition, the forthcoming National Dementia Strategy will address the needs of people with a learning disability to ensure inclusive care pathways.

Offender health

- 3.16** Research by the Prison Reform Trust, *No One Knows*, identified that 20–30% of offenders have learning difficulties or learning disabilities that interfere with their ability to cope within the criminal justice system. Prison workers' learning disability awareness training will be provided to all prisons in 2008/09.

64 www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_079987

65 www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4009598

- 3.17** PCTs need to work with their local prisons to ensure that offenders with learning disabilities, including young offenders have access to a full range of healthcare, including annual health checks and health action plans.

Example of good practice

In Southampton, a group of people with learning disabilities who use mental health services got involved and thought about the different sections of the 'Green Light' toolkit.⁶⁶ We had a project worker who met with them and other people with learning disabilities and their carers and checked that they were happy with the report he wrote.

The group then co-led the days when we presented the findings to professionals and they received an award from the National Institute for Mental Health (England) for their work in the Learning Disability and Mental Health section. The criteria for this category was for an initiative/innovation which demonstrated positive practice by addressing the mental health needs of people with learning disabilities.

The group is developing leaflets to provide information about mental health and mental illness for other people who use services. Members feed back that they can talk to and help other people with learning disabilities who are experiencing mental health problems. They feel that the group is a way of making sure that their experience counts and that their views are listened to. It is a way of supporting people to understand their illness and to receive information that is easy to understand. They say that, with the right support and opportunities, people with learning disabilities and mental health problems can participate and contribute to service development and improvements.

Making it happen locally and regionally – key recommended actions

- SHAs, PCTs and NHS Trust providers to address the recommendations in *Healthcare for All* and the Government's response, particularly in ensuring that reasonable adjustments are made to all health services to reflect the specific needs of people with learning disabilities.

66 <http://valuingpeople.gov.uk/dynamic/valuingpeople146.jsp>

- Partnership boards and PCTs to ensure people with learning disabilities and their family carers are partners in improving healthcare for people with learning disabilities.
- All relevant bodies to follow the guidance and/or use toolkits around health services for people with learning disabilities. This includes the *Specialist Learning Disabilities Commissioning Guidance 2007* and *World Class Commissioning guide for people with learning disabilities* published alongside this strategy and guidance on mental health, health action planning and health facilitation.
- PCT and NHS Trust disability equality schemes to include specific action to address health inequalities facing people with learning disabilities.
- SHAs and PCTs to support local services to address good practice for local services, as outlined in *Healthcare for All*.
- The National Directors and Valuing People regional teams will ensure that learning from the Mersey Care pilot site on human rights in healthcare is disseminated.

National level actions for government departments

- DH will produce guidance for the NHS on the Disability Equality Duty.
- DH will deliver the actions outlined above in response to the recommendations in *Healthcare for All* on information systems (recommendation 2), a Public Health Observatory function and Confidential Inquiry (recommendation 5), improving regulation (recommendation 6) and improving PCT commissioning of services (recommendation 8).
- DH will work with SHAs to support PCTs in commissioning services and developing care pathways in ways that address the needs of people with a learning disability.
- DH will work with the NHS Confederation to support the delivery of improved healthcare for people with learning disabilities, including the sharing of best practice. Commissioning and the quality of acute services will be a key focus to develop better understanding and improved response from the NHS. This will be part of a two-year joint programme.

- DH will work with professional regulatory bodies and education bodies to ensure awareness of the needs of people with a learning disability are incorporated into training for all healthcare professionals.
- Future developments in mental health policy and delivery will address the mental health needs of people with learning disabilities.

II. A home of your own

Overall policy objective: All people with learning disabilities and their families have the opportunity to make an informed choice about where, and with whom, they live.

3.18 Many people with learning disabilities – unlike the rest of the population – do not choose where they live or with whom. More than half live with their families, and most of the remainder live in residential care. Whilst undoubtedly both these options suit some people, many others are denied the opportunities and choices that are theirs by right. Residential care should continue to be available for those who actively choose it, but more emphasis needs to be placed on alternative ways of providing the housing that people want, and the support they need to live in it.

People with learning disabilities	General population
<ul style="list-style-type: none"> • 50–55% live in the family home • 30% live in residential care • 15% rent their own home 	<ul style="list-style-type: none"> • 70% own their own home • 29% rent their own home

3.19 People with learning disabilities and their families need to consider how to match their aspirations, both in the long and short terms, with the different sorts of housing and support that can be made available. At the same time, those who plan and commission services should consider how they could develop creative solutions to meeting those aspirations. Possibilities include people with learning disabilities being supported to live in their own home as owners or tenants; being supported to share with a group of friends; or living in residential care.

3.20 Living in your own home does not mean living without support, or being over-dependent on help from family members. This is not always

understood and the misunderstanding can cause unnecessary concern and anxiety to people themselves as well as to their families.

- 3.21** Home ownership and assured tenancies have to be matched and coordinated with a package of care specifically designed to support the particular individual in the home of their choice. Independent supported living can be enjoyed by people with very high or complex needs as well as those with fewer needs, because the support is tailored to their particular requirements. This was identified in the evaluation of DH's extra care housing pilot programme for people with learning disabilities, *A Measure of Success* (CSIP, 2008).⁶⁷
- 3.22** Some people with learning disabilities who have their own tenancies still sometimes find that their rights as tenants are overlooked or ignored on a routine basis. People with learning disabilities have the same rights in law as other people.
- 3.23** People assessed and funded as needing NHS continuing care can and should be supported to stay in their own homes, with intensive health input as required.
- 3.24** PSA 16 (see text box on page 80) measures the progress in the numbers of adults with learning disabilities known to social services moving into settled accommodation (ie not living in NHS campuses or residential care). This is a delivery priority for Government and local authorities.
- 3.25** *Our Health, Our Care, Our Say*⁶⁸ said that all NHS campuses should close by 2010. In 2007, DH announced a three-year £175 million capital fund to help develop appropriate housing for people leaving campus accommodation. Additional revenue funding will be provided: £96 million over the three years to 2010/11.

67 <http://networks.csip.org.uk/IndependentLivingChoices/Housing/Topics/browse/LearningDisabilities/>

68 *Our Health, Our Care, Our Say*, Department of Health (2006)

Public Service Agreement PSA 16

The Socially Excluded Adults Public Service Agreement target (PSA 16 target) was announced in October 2007 as part of the Comprehensive Spending Review, and as such is one of Government's top 30 priorities for 2007–10. The PSA is led by the Cabinet Office and owned jointly by DH, DWP, CLG, DCSF, Department for Innovation, Universities and Skills (DIUS) and the Ministry of Justice.

Evidence shows that without the firm foundations of a settled home and job, the most disadvantaged adults risk a lifetime of social exclusion for themselves and their children, and potentially place a lifetime cost on society. The Government is committed to ensuring that socially excluded adults are offered the chance to get back on a path to a more successful life, by increasing the proportion in settled accommodation and in employment.

The PSA focuses on four client groups who are particularly at risk of exclusion. While these groups can be highly vulnerable, they are also in contact with services that could and should make a difference. They are:

- young adults leaving care;
- adult offenders under probation supervision;
- adults receiving secondary mental health services; and
- adults with learning disabilities known to councils.

All of the PSA indicators are also included in the latest local government performance framework. All local authorities have to report on them, and some are setting themselves specific improvement targets through the Local Area Agreement process.

3.26 Housing related support, through the Supporting People programme, already helps many people with learning disabilities to live in their own home through the provision of housing related support services. People with learning disabilities will continue to benefit from locally planned and delivered housing related support to help individuals live as independently as possible. The Supporting People outcomes set is a measurement tool designed to test the effectiveness of housing related support services. It provides all service users, including people with learning disabilities, with the opportunity to decide, in collaboration

with their service provider, which outcomes their support services should bring about for them.

3.27 The Housing Corporation's 2008–11 National Affordable Housing Programme has allocated over £340 million for the development of new supported housing. Its successor agency, the Homes and Communities Agency, is working closely with DH to identify future capital investment opportunities to develop a range of social home ownership options for people with learning disabilities.

3.28 The Government recognises that, for some people, housing design and management linked to their disability might increase costs above the local norm. What is required is a funding arrangement that does not put people's housing security at risk, is based on an assessment of individual need and reasonableness and achieves best value in terms of available housing for public expenditure. DWP is committed to reviewing the Housing Benefit Regulations in the longer term, and in the short term is producing guidance to Housing Benefit officers.

Making it happen locally and regionally – key recommended actions

- Joint Strategic Needs Assessments to identify the housing needs of people with learning disabilities to inform strategic planning, including the number of people with learning disabilities living with family carers over 70 and those with complex needs.
- Local authorities to facilitate people's access to housing of their choice including:
 - more people receiving personal budgets and Direct Payments to increase their choice and control over where they live and with whom;
 - local authority care managers to have an increased focus on home ownership and assured tenancies as a model for housing and support; and
 - through person centred planning, work with people still living with families to establish if that is the person's preferred option and to instigate plans accordingly.

- All local authorities are already required to produce a housing strategy reflecting local population housing needs, including those of people with learning disabilities. Government Offices to ensure that all local authorities have an appropriate housing strategy.
- Wherever possible, transition plans and year 9 reviews to address future accommodation choices.

National actions for government departments

- The Government is committed to delivering the PSA 16 objective on settled accommodation and will publish a delivery plan for this by summer 2009.
- CLG and DH will set up a programme of work, beginning in early 2009, to consider how mainstream housing policies can best be made inclusive of people with learning disabilities.
- DH and DWP will work together to address issues around housing benefit and support.
- DH will make capital and revenue funding available to PCTs and local authorities to help facilitate the closure of the NHS campuses.
- Care Services Efficiency Division (CSED) will undertake a programme of work starting in 2009/10 to support a market shift towards moving people from residential care into supported living.



III. Work, education and getting a life

Overall policy objectives: All people and their families to have a fulfilling life of their own, beyond services, that includes opportunities to work, study, and enjoy leisure and social activities. This includes supporting more people with learning disabilities into paid work, including those with more complex needs.

3.29 People with learning disabilities want to lead ordinary lives and do the things that most people take for granted. They want to study at college, get a job, have relationships and friendships, and enjoy leisure and social activities. Many people need support to do these things; and some will need high levels of support on an ongoing basis as well as multi-agency investment to have any kind of meaningful life. Experience has shown that more opportunities can be achieved for people if services:

- work in close partnership with families as well as other services and link into broader community developments through Local Strategic Partnerships (LSPs) and Local Area Agreements (LAAs);
- think beyond nine-to-five working days and include evenings and weekends;
- see planning for employment as a key objective in person centred plans, including person centred transition plans;
- recognise the importance of working with schools and colleges to ensure a positive transition to adulthood for young people;
- recognise the importance of planning for people who are past the retirement age and may want things other than work;
- invest in making community-based facilities and settings that are accessible for all; and
- develop a clear de-commissioning strategy that shows how money will be drawn down from traditional services and re-invested in wider opportunities.

3.30 However, employment levels for people with learning disabilities remain low, with less than 10% of people known to services in paid work and very few of them working more than a few hours a week.

3.31 Access to post-16 education has been a problem because of priority being given to young people and achieving level two qualifications, which excludes people, especially those with more complex needs. This has meant the end of any further education opportunities for some people, rather than the start of improved new ones.

3.32 Families and young people have said that transition planning does not support them well for the move to adulthood. Many young people are not achieving the same outcomes as other young people – ie an education, a job, friends and a good social life.

Transition

3.33 The government is committed to supporting local authorities and partner agencies develop a person centred approach to the statutory transition planning process.

3.34 To help deliver the promise in the NSF for Children, Families and Maternity Services, the Person Centred Transition Programme led by the Valuing People team has been introducing person centred approaches into the statutory transition planning process. Parents and young people say that they feel involved for the first time and outcomes for young people are beginning to change. The further education sector is now adopting this approach in some areas.

'Conducting Alex's meeting in this way made a real difference to both Alex and myself; instead of feeling let down, anxious and on the side line, we felt included, listened to, and I really felt part of a big team, working together to give Alex the best future possible. Alex was also much happier in school because he had been listened to and all of his worries and concerns were addressed and understood. In fact, everyone who attended this meeting found it to be much better, more informative and a fun way of conducting reviews, which really include the child.'

A mum whose son had a person centred review

3.35 *Aiming High for Disabled Children* announced funds of £19 million for the Transition Support Programme (TSP) until March 2011. The programme is being designed to improve processes for supporting disabled young people through transition on the ground in local areas, to help ensure that all areas meet at least minimum standards of provision and with many areas achieving good practice in transition support.

- 3.36** The DCSF has contracted with the Council for Disabled Children and its partners working as the national transition support team to coordinate activity and maximise the impact of the TSP in local areas linking with existing regional adviser teams. The objectives of the TSP are: disabled young people and families are able to report improvements in their experience of, and in time, improved outcomes from, transition; the processes to support transition improve nationally; support for transition provided by local areas is more consistent; and local authorities, PCTs and schools show increased expertise in transition.
- 3.37** In October 2007, DCSF and DH jointly published *A transition guide for all services*,⁶⁹ written by the Council for Disabled Children. This provides an overarching view of all the services that need to work together to ensure appropriate support for disabled children throughout each stage of their life.
- 3.38** In February 2008, DH and DCSF published *Transition: moving on well, A good practice guide for health professionals and their partners on transition planning for young people with complex health needs or a disability*.⁷⁰ This established a network of health professional champions who will promote good transition planning in partnership with other agencies and young people and families. DH will continue to promote the introduction of person centred planning approaches into the statutory transition planning process.

Post-16 education

- 3.39** In June 2007, the then Department for Education and Skills (now DIUS and DCSF) published *Progression Through Partnership*, a joint strategy with DH and DWP. This strategy set out a five-year programme of change which includes:
- starting from the position that people with learning disabilities can learn, benefit from learning and should progress to paid employment;
 - improving the experience and quality of transition to adulthood;
 - ensuring the curriculum followed by learners is high quality, can be accredited and provides positive outcomes; and
 - improving the clarity and flexibility of funding to support learning, basing this on a person centred planning approach to the task.

69 www.everychildmatters.gov.uk/_files/TransitionGuide.pdf

70 www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_083592

- 3.40** From 2010, the Learning and Skills Council will cease to exist; responsibility for the planning, commissioning and delivery of the further education system will pass to local authorities. Funding for the sector will pass to local authorities via two new agencies: the Young Persons Learning Agency (covering 16–19) operated by DCSF and the Skills Funding Agency (covering 19+) operated by DIUS. For learners with learning difficulties and/or disabilities, local authorities will retain responsibility for full-time learners up to the age of 25, to ensure continuity of support and provision. These new arrangements will be subject to legislation in 2009.
- 3.41** From 2010, the Foundation Learning Tier will be introduced. This is a qualification and curriculum framework which will offer new pathways giving recognition to all learning offered below level 2. Learners will be able to follow courses which offer accreditation for their learning which can be followed at a pace suited to their needs and talents. With an emphasis on employability skills, the framework will provide preparation for independent living. The Foundation Learning Tier is an all-age framework, so learning can be picked up throughout life. This may well be of considerable help to those who need to pick up learning again or need to consider re-training.
- 3.42** DH will continue to work with DCSF, DIUS and DWP to fully implement Progression through Partnership, including ensuring that meaningful and relevant learning opportunities are accessible, and that imminent changes to the funding of all post-16 education benefit all people with learning disabilities.

Employment

- 3.43** Work defines us: what will you be when you grow up? What do you do for a living? These are questions we all face from others when people want to get to know us. But they are questions seldom directed towards people with learning disabilities. Because so few people with learning disabilities do work, there is no expectation from others that they can, and consequently little is done to offer them the opportunity.
- 3.44** PSA 16 provides the delivery agreement and performance indicators aimed at getting more adults with learning disabilities known to councils into paid employment. A priority for *Valuing People Now* and the PSA delivery plan will be the cross-government strategy on employment of people with learning disabilities which will be published in spring 2009.

Implementing this strategy will be a priority for government departments and their delivery agents, and innovative practice needs to be showcased to challenge the assumptions that people with moderate to severe learning disabilities cannot work.

3.45 The biggest challenge for the strategy will be to help people, their carers, and the staff and services that support them to believe that work is a genuine possibility, when they see few examples of it in practice. The evidence from some parts of both the USA and the UK is that even people with more complex needs can be supported to work successfully in paid jobs. But to achieve it, the belief has to be there, and the expectation built into schools, colleges, and adult social care and employment services. This will require some fundamental changes in the way all these services work and interact with each other.

3.46 The key themes in the developing employment strategy will be:

1. The presumption of employability. Without the belief that people can work, the evidence is that the right information, coaching and support that is required to help people get jobs will not be put in place.



2. A person centred pathway, focused on getting individual people a job, that starts early in schools and continues into adulthood. This will require the identification of a 'lead professional' to make sure it happens and is implemented by connecting them to the delivery chain.
3. Access to the customised employment that is necessary to make sure the person's employment needs are worked on in depth and matched to an in depth analysis of the employer's needs.
4. The braiding of funding streams from different services, using individual budgets, to ensure maximum cost-effectiveness and flexibility in the delivery of appropriate individual job coaching, job development and, where necessary, long-term job support.
5. Engagement with employers at a local level, to identify their needs, demonstrate to them the business case for employing people and get their support in raising expectations.

3.47 Employment is not the responsibility of any single service or department. The strategy will only succeed if there is a shared expectation that more people with learning disabilities can and will work, and if the adjustments are made in the way services work together to achieve this.

3.48 The employment strategy will build on the commitments already announced in the Social Mobility White Paper *New Opportunities*,⁷¹ to pilot a support broker role to help people use their individual budgets for employment support, embed supported employment in the new Foundation Learning Tier, consider employment awareness training for family carers and expand the Getting a Life demonstration programme to every region.

'We are clear that the new specialist disability employment programmes must meet the specific needs of those furthest from the labour market. We recognise that those with moderate to severe learning disabilities, for example, may need specialist support; and may need this support to continue at some level for as long as the individual is in work. We are clear that the new contracting arrangements must allow for this specialist provision.'

Welfare Reform Green Paper, July 2008

71 *New Opportunities: Fair chances for the future*, Cabinet Office, Cm 7533 (2009)

- 3.49** The Green Paper *No one written off: reforming welfare to reward responsibility* (DWP, July 2008)⁷² announced a doubling of the Access to Work budget, to £138 million by 2013/14 to enable DWP to expand the reach of the programme, and to help more employers and more disabled people seeking help to start and/or retain their jobs. DWP will press ahead with the proposed reform to introduce a single programme that supports disabled people who have complex barriers to finding and starting work. This will bring the current Job Introduction Scheme, WORKSTEP, and Work Preparation budgets together to create a seamless employment programme which will help those furthest from the labour market – including people with learning disabilities – into work.
- 3.50** The cross-government *Getting a Life* programme is working with 10 demonstration sites to achieve an integrated assessment and decision-making process that will allow people to use public resources flexibly to get the outcomes they want, which will include access to paid employment opportunities. The initial focus of the work will be on young people going through transition. Sites will demonstrate good practice in relation to helping young people with learning disabilities to achieve paid employment and full lives, and to inform government of barriers and solutions. Learning from the programme will be shared quickly so that other parts of the country can take on new ideas at an early date (see text box on page 90).
- 3.51** The Civil Service recognises that it also needs to lead by example in employing more people with a learning disability. DH is leading a work programme to increase the number of adults with learning disabilities employed in the NHS.

72 www.dwp.gov.uk/welfarereform/noonewrittenoff/

Getting a Life

Getting a Life is a three-year cross-government programme that aims to identify what needs to happen in order to ensure that young people with severe learning disabilities leave education and go on to achieve paid employment and full lives.

Getting a Life receives support and funding from DCSF, DIUS, DWP, ODI and DH.

There are 10 demonstration sites: Norfolk, South East STAG (Strategic Transition Group) with Kent and Medway, Richmond, Somerset, ROC with Torbay, Herefordshire, Oldham and Manchester.

The sites will work with approximately 30 young people aged 14–25 who have severe learning disabilities. Each demonstration site has a multi-agency project team that includes young people and their families alongside senior decision makers from schools, colleges, children and adult services in local authorities, Jobcentre Plus, Connexions, Learning and Skills Council and supported employment agencies.

The Getting a Life programme will:

- identify and demonstrate good practice in relation to enabling young people with severe learning disabilities to leave school or college and go into paid employment and have full adult lives;
- explore how to bring together assessment and funding streams from the four different national and local policy areas (Special Educational Needs assessment and transition planning, Connexions, Learning and Skills Council and post-16 education, Jobcentre Plus and adult social care assessment and resources) so that young people can use public resources flexibly to get the outcomes they want;
- inform government about what works and what needs to change at a policy level;
- develop a learning community to gather good practice and to share this widely; and
- support the sites to work with approximately 30 young people aged 14–25 who have severe learning disabilities.

Under the Social Mobility White Paper *New Opportunities* we will extend the Getting a Life programme to all nine regions by adding two more sites.

Making it happen locally and regionally – key recommended actions

- All partnership boards to ensure that by 2012 all young people with statements of Special Educational Need who have learning disabilities have person centred reviews from age 14 to 19 that actively involve the young person and their family.
- Valuing People regional team will work with the Transition Support Programme to support all local areas to achieve minimum standards in transition planning and support.
- All transition plans and year 9 reviews where appropriate to contain a section on health needs and start the development of a health action plan.
- Every local area to have a multi-agency employment strategy, linked to PSA 16.
- Partnership boards to make sure that access to the post-16 education and training sector is fully included in the local strategy for responsibilities returning to local authorities.
- There will be a transition lead in every region who will support the delivery of a regional multi-agency transition strategy, supported by an implementation group involving all key stakeholders, in particular young people and their families.

National level actions for government departments

- A cross-government strategy on the employment of people with learning disabilities will be published in spring 2009.
- The National Directors will appoint national leads for transition and employment. They will work closely with DCSF and DWP and will lead programmes of work to identify the additional supports and facilities that may be required to build capacity and capability to enable local services to deliver objectives. A key activity will be to ensure strong linkages between the work around post-16 education and employment, so that transition reviews focus on employment opportunities and appropriate training for young people leaving school.
- DH and DCSF will work together to ensure that *Aiming High for Disabled Children* and the Transition Support Programme will support local areas to improve their transitions arrangements and consolidate person centred approaches, working closely with adult social services.

- DH and DCSF will publish joint guidance for schools, colleges, local authorities and local Learning and Skills Councils on preparing for the changes to funding arrangements and systems are in place to deliver the vision of social inclusion as part of the delivery of *Progression through Partnership*.
- The National Directors will continue to lead and manage the Getting a Life programme, and ensure that the learning is captured and disseminated to inform policy and practice.
- The cross-government Work, Education and Life working group will lead implementation of the cross-government employment strategy and will oversee the Getting a Life programme.
- The National Directors will liaise with the Office of the Third Sector to ensure that volunteering opportunities are open to people with learning disabilities.
- DH will develop and test a support broker role as a lead professional for adults with moderate to severe learning disabilities. Support brokers will be introduced in a number of areas from September 2009. Their success in ensuring that a range of client needs are addressed, and housing and employment outcomes are improved, will be evaluated through to 2011.

IV. Relationships and having a family

Overall policy objective: People with learning disabilities have the choice to have relationships, become parents and continue to be parents, and are supported to do so.

3.52 Like everyone else, people with learning disabilities tell us that relationships are important to them, both friendships and relationships of a personal and sexual nature. Yet the evidence is that people with learning disabilities have very few relationships and limited opportunities to form or sustain them. People are often lonely. One of the reasons for this is their exclusion from the kinds of places where other people form and maintain relationships, such as work, college, clubs, places of worship, leisure centres, etc, but there are other reasons for this, mostly based on assumptions about people with learning disabilities.

3.53 The right to marry or have a civil partnership is both a civil and human right; local systems should enable practice that supports the individual's choice with regard to forming and sustaining relationships.

3.54 Supporting peoples' rights to have relationships is mostly about challenging stereotypes and changing attitudes. Some specific reasons for why people with learning disabilities have limited relationships are:

- the way in which professionals take decisions about service delivery that ignore existing relationships and break up friendship patterns, eg when people are moved from one service to another;
- insufficient consideration being given to personal relationships in individual planning and care management processes;
- services getting the balance wrong between protecting vulnerable people and helping people have a life: positive risk taking should be a part of everyone's life, including those with more complex needs; and
- many people still not recognising and accepting that people with learning disabilities, like anyone else, want and need personal and sexual relationships.

Making it happen locally and regionally – key recommended actions

- Valuing People regional leads will work with partnership boards to support local service commissioners and providers to develop systems and processes which will enable people with learning disabilities to build and sustain relationships.

National level actions for government departments

- The National Directors will work with CSCI (and subsequently the Care Quality Commission) to address the role of registered care services in supporting people to develop and sustain relationships, including sexual relationships, increasing access to mainstream leisure and recreational services, and supporting people to keep in contact with their friends and families.
- The National Directors and Valuing People regional team will produce toolkits for health and social care professionals about promoting safe relationships within the laws of safeguarding and human rights.

V. Parents with a Learning Disability

- 3.55** *Valuing People* highlighted the need for services to support parents with a learning disability. Evidence suggests that such parents do not get sufficient access to support, putting families at risk of enforced separation. Indeed, such parents are at a disproportionate risk of losing their children into care.
- 3.56** We need to do more to make sure that adults' and children's services work more effectively together to improve identification of families that need extra support and carry out more effective assessments of their needs to ensure that families with complex needs, including parents with learning disabilities, receive the right level of support at an earlier stage. *Think Family: Improving the life chances of families at risk*⁷³, set out a vision for an integrated system which looks at circumstances of the whole family enabling them to intervene and provide support more consistently by introducing better systems for identifying and engaging families and improving information sharing between service providers. We have begun to implement this vision through the Family Pathfinders, and we will take learning from these projects and work with all local authorities to implement better integrated adults' and children's services in all local authorities.
- 3.57** The Parenting Implementation Project (PIP) is working with a number of local authorities to develop good practice in relation to the commissioning and implementation of parenting and family support services. This good practice and learning will be shared more widely with other local authorities to support them in developing services that can meet the diverse needs of all parents in their area.
- 3.58** As part of the project, some local authorities are developing resources which will share good practice around joint working with adult services to best support vulnerable parents. We are also developing good practice around the training and development of the children's and parenting workforce to enable them to recognise and support the varying and diverse needs of families. We have held discussions with these local authorities and stakeholders about the needs of parents with disabilities, including those with learning disabilities. This debate has supported the development of the Parenting Implementation Project projects and informed policy development in this area.

73 *Think Family: Improving the life chances of families at risk*. Cabinet Office (2008)

- 3.59** We are also working more widely with local authorities to build capacity to develop robust needs-based strategies which will enable them to support vulnerable parents, including those with learning disabilities.
- 3.60** *Putting People First* identifies supporting disabled people to sustain a family unit as one of its outcomes. The Government has a significant programme of work aimed at supporting parents generally, and a range of initiatives aimed at groups of parents experiencing particular difficulties. These include:
- Family Intervention projects (DCSF);
 - work with the *Working Together with Parents Network*⁷⁴ (DH) to develop good practice guidance for commissioners of adults services;
 - dissemination of the joint *Good practice guidance on working with parents with learning disabilities* (DfES and DH, 2007).⁷⁵
- 3.61** It is important that relevant professionals have training in the effective implementation of this joint guidance, and DCSF will be working closely with local authorities and Government Offices to ensure that frameworks are in place for this to happen.
- 3.62** The Social Care Institute for Excellence (SCIE)⁷⁶ has carried out a knowledge review and developed a resource guide for joint working across children's and adult services to support disabled parents.
- 3.63** More needs to be done to ensure that parents with a learning disability receive support and benefit from all mainstream initiatives aimed at parents. Research evidence highlights the need for independent advocacy when parents with learning disabilities are at risk. Parents with learning disabilities also need to have access to the same level of information and advice available for all parents.

74 Working Together with Parents Network – see www.bristol.ac.uk/norahfry/right-support/

75 www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/DH_075119

76 www.scie.org.uk/publications/guides/guide19/index.asp

Joint Committee on Human Rights

The issue of parents with learning disabilities having access to a family life with their children was a far-reaching feature of the Joint Parliamentary Committee on the Human Rights of Adults with a Learning Disability (2008). The Committee's report, *A Life Like Any Other?*, reinforced that, 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 respect for their family life under Article 8 of the European Convention on Human Rights and the Human Rights Act 1998. The report stated that if the recommendations in the joint *Good practice guidance on working with parents with learning disabilities* (DfES and DH, 2007) were implemented effectively, it would significantly reduce the risk that parents and their children would be separated in breach of the convention.

3.64 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.

'They explain things in words you don't understand and you think help I don't understand what she's saying and you ask her to say it again and she uses the same language and I feel really stupid because I still don't understand but I don't feel I can ask her to say it again.'

Parent with a learning disability, *Good practice guidance*
(DfES and DH, 2007)

Making it happen locally and regionally – key recommended actions

- All relevant bodies (PCTs, LAs, etc) to ensure that they are using accessible information when supporting parents with a learning disability and that their services are accessible, as required by disability discrimination legislation.
- Local authorities to use personal budgets and direct payments to support parents with a learning disability as part of their Transforming Social Care strategies.
- All local authorities working with DCSF to implement *Think Family* reforms to make sure that adults, and children's services understand how to support families experiencing difficulties and deliver a joined up service.

National level actions for government departments

- The National Directors will work with all relevant government departments to ensure that all information for parents with a learning disability is available in accessible formats where appropriate.
- DCSF will further disseminate the joint *Good practice guidance on supporting parents with a learning disability*.
- The National Directors and DCSF will disseminate the SCIE resource guide.
- The Working Together with Parents Network will develop new good practice guidance for commissioners of adult services in early 2009, followed by guidance for children's services; DH (Office of the National Director) and DCSF will disseminate these.

Chapter 4: People as citizens



Overall policy objective: People with learning disabilities will be treated as equal citizens in society and supported to enact their rights and fulfil their responsibilities

I. Advocacy

Overall policy objective: All people with learning disabilities can speak up and be heard about what they want from their lives – the big decisions and the everyday choices. If they need support to do this, they should be able to get it.

4.1 People with learning disabilities say that being part of a self-advocacy group or getting support from an advocate is a really important part of being able to take control of their lives. There are different types of advocacy, including:

- self-advocacy – people coming together to speak up for themselves;
- citizen advocacy – volunteers developing long-term relationships with people and speaking up for them;
- professional or representational advocacy – people being paid to advocate with, and for, individuals on a short- or long-term basis; and
- peer advocacy – people who have the same or similar experience of discrimination as the person they are acting as an advocate for.



Terry's story

Terry is 19 years old and lives with his mother. He has been going to a self-advocacy group and recently they talked about *Valuing People Now: Better housing to live in*. Terry has been thinking about moving out of his house for some time. Terry's mother Louise has lots of worries and concerns about where he will live; whether he will live on his own or who he may share with; how Terry will stay safe. Terry sometimes has epileptic fits but really wants to be independent. Like most 19-year-old young men, Terry just wants the chance to live a full and active life.

The advocate meets with Terry to talk to him and help him plan for the future and the first step is talking about his worries. Terry is worried that he will not get the right amount of support; he does not want to have someone with him all the time but his mother Louise thinks that he should. Both Terry and Louise want to know what will happen to Terry if he has a fit.

The advocate talks to Terry about the support that he feels he would need, and what would help him feel safe. The advocate also talks to Terry about what he enjoys doing in his life and about his dreams for the future. They talk about different kinds of house and places that he could live in by getting pictures of different kinds of houses and areas around the city. The advocate also talks about renting and shared ownership. Terry is really interested in owning his own home and asks the advocate to help him talk to his mum and explain things to her. Louise is excited about the idea of Terry owning his own home as this was not something she thought would be possible. Talking with Terry and the advocate helps Louise think about her worries and concerns.

The advocate discusses the possibility of Terry getting an Individual Budget with his social worker and organises a meeting with a Support Planner to help facilitate a more detailed individual support plan with Terry. The advocate also organises a meeting with Supporting People to discuss how they can help Terry stay safe but independent in his own home using Telecare, Telehealth and Community Alarm System.

Six months later, Terry and his mum are looking at houses for Terry near his mum, and are working with the advocate and their local Centre for Independent Living to think about how best to organise Terry's Individual Budget to make sure he can get the support he needs. Terry has asked a friend from college to share with him and they hope to be moved in very soon.

- 4.2** Government policy is clear that people should be able to be active citizens and have a say about how things work where they live (*Communities in control: Real people, real power* – White Paper, July 2008). It also recognises that some people need support to make this happen. There are specific rights in law for advocacy in some circumstances:
- the Mental Capacity Act 2005: this provides a statutory framework for acting and making decisions on behalf of individuals who lack the mental capacity to do so for themselves. The Independent Mental Capacity Advocate (IMCA) service supports people who lack capacity and who have no family or friends to support them when serious decisions are taken in their lives; and
 - the Mental Health Act 2007: arrangements will be made to provide Independent Mental Health Advocates (IMHA) for ‘qualifying’ patients in England from April 2009.
- 4.3** In addition, the joint (DfES and DH, 2007) guidance on supporting 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 proceeding. It also says that advocacy and self-advocacy should be made available to help parents engage with, and access, services.
- 4.4** The number and range of advocacy organisations have grown since 2001. Local authorities now spend on average £106,000 on advocacy for people with learning disabilities compared to £74,000 in 2004. But people who fund advocacy don’t always know whether the money they spend is really helping people with learning disabilities to stay in control of their lives. Advocacy organisations need to be able to show that the money they receive has made a positive difference and that people are getting better services and support.
- 4.5** Being able to speak up about decisions which affect your life relies on being given the right information to make those choices. For this reason *Putting People First* says that people who need support in their lives should have access to better support, information and advocacy so that they are able to navigate the health and social care systems. Accessible information for people with learning disabilities is a crucial part of this and a set of standards for producing and commissioning easier to understand information will be published in early 2009.

Making it happen locally and regionally – key recommended actions

- Regional Valuing People leads will drive a programme of leadership support involving the national and regional forums to build and strengthen self-advocate leaders.
- Partnership boards to develop an information strategy to publicise the availability of advocacy regionally and locally and share best practice.
- Local Involvement Networks (LINKs) will encourage engagement of partnership boards and people with learning disabilities in their activities.
- Regional Valuing People leads will support service commissioners to help them commission a broad range of high-quality advocacy services and support.

National level actions for government departments

- The National Directors will appoint a programme lead for advocacy to ensure that the national advocacy programme and funding focuses on supporting advocacy to achieve a greater impact, including:
 - a tool for self-advocacy groups;
 - work to support advocacy for people from black and minority ethnic communities and people with complex needs; and
 - strengthening leadership support for people with learning disabilities in every region to build and strengthen self-advocate leaders and support the development of strong advocacy support.
- The National Directors will lead on work to ensure that government information for people with learning disabilities is made available in accessible formats.

II. Transport

Overall policy objective: By 2011, people with learning disabilities will be able to use public transport safely and easily and will feel confident about doing so

- 4.6** Being able to use public transport is vital in connecting people to jobs, services and social networks. Lack of access to good, regular and accessible transport seriously impacts on people's ability to get and keep jobs and friends or get an education.

4.7 The Disability Discrimination Act 2005 requires all new trains, buses and coaches to be accessible to disabled people and there has been some good progress towards an accessible public transport system. Since December 2006, it has been illegal for transport operators to discriminate against disabled people or fail to make a reasonable adjustment. But action has largely focused on physical access. People with learning disabilities face additional barriers, in particular the lack of accessible information, staff attitudes and harassment (or the fear of harassment). DfT has produced best practice guidance for transport providers on the provision of information for disabled people, *Inclusive Mobility*.⁷⁷

Colin used taxis to get him to his schools and college. Once Colin finished education, he became socially isolated in his village as no funding was available to allow him to access things he wished to do. He was effectively stuck in the village, the only time he went out being when he went with his carers. Two years ago (when Colin was 27) he was referred for travel training as he had been offered a place at CASE training service.

CASE is an accredited training organisation providing meaningful, effective training and work experience opportunities. Trainees develop vocational and other skills at their own pace with the aim of improving quality of life and enhancing future prospects. Everyone who attends CASE needs to transport themselves to and from the centre.

Colin adds:

'After having my travel training, I felt a lot more confident and began to catch the bus into Beverley. After my training I began to catch the bus into Hull too. I now come through to Hull every Saturday to meet up with my friends from CASE. We go to the café and look around the shops. It makes me feel proud of what I can do. I think it's a good idea for others to try to learn how to travel independently.'

4.8 DfT has issued guidance on how local authorities should publish their local transport plans and annual reports in order to make them accessible to disabled people.

⁷⁷ *Inclusive Mobility – A guide to best practice on access to pedestrian and transport infrastructure*
www.dft.gov.uk/transportforyou/access/peti/inclusivemobility

Making it happen locally and regionally – key recommended actions

- Learning Disability Partnership Boards to engage with local transport plans to ensure the effective inclusion of people with learning disabilities.
- Valuing People regional leads will support local systems to address the range of support people need to travel, investment and issues around safety.

National level actions for government departments

- DfT and DH to ensure national programmes on inclusive transport include people with learning disabilities.
- DfT is leading a strand of work around information and confidence training for disabled people as a response to the Independent Living Strategy.
- DfT is working with transport operators to support them in offering and improving disability awareness training.
- DfT's Disabled Persons Transport Advisory Committee (DPTAC) has produced guidance material to the transport industry which we will be promoting.

III Access to leisure services and recreational activities

- 4.9** Many people with learning disabilities find it difficult to use local mainstream services such as leisure centres, sports facilities, libraries, cinemas, restaurants and shopping centres. This may be about inaccessible facilities, but it is also about lack of accessible information or signposting, unwelcoming attitudes or, in some cases, lack of appropriate support for those who cannot travel or participate without it. Public services need to be mindful of their Disability Equality Duty and proactive in providing information about their facilities or programmes that is easy to understand.
- 4.10** People with more complex needs are often not connected to their communities, or given any meaningful programme of vocational, social, leisure or learning activities. New initiatives such as the Life in the

Community⁷⁸ project and Changing Places (see text box on page 107) demonstrate that this does not need to be the case.

- 4.11** Another challenge is how to provide meaningful learning opportunities for people with learning disabilities who want to re-enter adult education in later life or take up learning programmes for recreation only.

Making it happen locally and regionally – recommended key actions

- Local authorities and their partners will include leisure and social activities in developing person centred approaches and planning for people with learning disabilities and their families.

National level actions for government departments

- DH will work with the Department for Culture, Media and Sport to explore how local leisure services can be made more accessible for people with learning disabilities.



78 Foundation for People with Learning Disabilities, Life in the Community. See: www.learningdisabilities.org.uk/our-work/community-and-inclusion/life-in-the-community/

Changing Places

The Changing Places campaign is calling for fully accessible toilets – with a changing bench, hoist and plenty of space – to be installed in all big public places in the UK.

As Bethan, mum to Lowri who has profound and multiple learning disabilities, explains:

'Without Changing Places toilets it is a nightmare. We try to plan our days around being home for meal times because Lowri needs to go to the toilet, meaning we can only spend a few hours away from home. We have a large mat which we carry around in case we have to change her when we are out. We put this down on the floor of 'disabled' loos and just muddle through – we have countless experiences at eye level of disgusting toilet floors.'

Lowri is a wheelchair user with no independent mobility and needs complete 24-hour support with all aspects of her care. She wears continence pads which need to be changed in a Changing Places toilet. Bethan and Lowri's lives have been changed thanks to a Changing Places toilet being opened in Nottingham.



Thanks to the Changing Places campaign the number of Changing Places toilets in the UK has increased from eight to 58 in the last two years. But for the many thousands of families like Bethan's, this is not nearly enough.

For more information visit www.changing-places.org

IV. Being safe in the community and at home

Overall policy objective: People with learning disabilities will be able to lead their lives in safe environments and will feel confident that their right to live in safety is upheld by the criminal justice system.

Hate crime

- 4.12** People with learning disabilities tell us they have a right to live in safety and to be taken seriously when they complain about abuse or report a crime against them. The lives of too many people with learning disabilities are constrained by experience of abuse and neglect and many people have been victims of hate crime. People from black and minority ethnic groups and newly arrived communities are particularly at risk of hate crime. But evidence shows that when people do experience crime or abuse they often find it difficult to report it because police processes can be inaccessible and unwelcoming and they feel they may receive a poor response from the criminal justice system, who do not always understand how to work with or support people with learning disabilities.
- 4.13** The Disability Discrimination Act 2005 and the Human Rights Act 1998 provide a framework for ensuring that people with learning disabilities are not subjected to harassment, or worse, and have equal access to the criminal justice system. The Race Relations (Amendment) Act 2000 protects those from black and minority ethnic communities, and racially aggravated crimes are given enhanced sentences under the Crime and Disorder Act 1998. However, evidence shows that there is more to be done to protect people from hate crime.
- 4.14** The Government has become more informed about the problem of disability hate crime thanks to the National Forum for People with Learning Difficulties, which has been leading a campaign for action on disability hate crime. The Home Office, together with the Ministry of Justice and the Association of Chief Police Officers (ACPO), is leading on a number of related work strands as part of their Tackling Violence Action Plan (published in February 2008).⁷⁹ The plan will focus on tackling those offences causing the most harm and this includes disability hate crime. A key component of this plan is the development of a comprehensive, cross-cutting Government Hate Crime Strategy, including disability hate crime.

⁷⁹ www.homeoffice.gov.uk/about-us/news/violent-crime-action-plan

4.15 The Home Office has also funded two voluntary sector projects to raise awareness of hate crime and improve understanding and reporting of hate crime against people with learning disabilities:

- 'Learning Together', a project run by Inclusion North and Coast2Coast to assist local Learning Disability Partnerships, advocacy groups and community safety partnerships to improve understanding and reporting of hate crimes against people with learning disabilities; and
- distribution of the People In Partnership 'PIP' pack, designed by self-advocates to raise awareness of hate crime and personal safety (see below).

The People In Partnership 'PIP' pack, designed with people with learning disabilities, criminal justice and support agencies, contains information and tools for people to know about their rights, the law, how to keep safe, how to access the police and support services, and how to report crime.

The pack includes a Reporting Book with information about crime, hate crime and how to report it and an easy-to-use Reporting Form. This will be available for people with learning disabilities across the country to report crime and hate crime through police forces and True Vision.

4.16 Other key work strands within the criminal justice system as part of the work led by Race for Justice⁸⁰ include:

- improved data collection and monitoring of disability hate crime;
- the development of new minimum standards of investigation into disability hate crime for police;
- the development of new standards for criminal justice system professionals working on disability hate crime and a training needs analysis for police.

4.17 Work led by the criminal justice departments (Home Office, CPS, MoJ and the Attorney General's Office) includes the introduction of special measures for disabled witnesses, including:

80 See glossary

- aids to communication – this will be permitted to enable witnesses to give their best evidence whether through a communicator or interpreter, or through a communication aid or technique, provided that this can be independently verified and understood by the court;
- the use of an intermediary – someone who can help a vulnerable witness understand questions they are asked and who can then communicate the witness’s response to the court; and
- assessing the types of support available to victims with learning disabilities and which organisations might provide this support.

Safeguarding

4.18 DH has published a consultation on the review of the *No Secrets* guidance on safeguarding vulnerable adults.⁸¹ As part of this consultation the Department will specifically talk to adults with learning disabilities.

Making it happen locally and regionally – recommended key actions

- Valuing People regional leads will work to support local authorities in responding to the consultation document *Safeguarding Adults: A Consultation on the Review of the ‘No Secrets’ Guidance* and then with the outcomes of the consultation.
- Government Offices (HO lead) will support partnership boards to engage with local crime and disorder partnerships and to identify a hate crime lead and a link person responsible for working with the Safeguarding Boards.
- Crime and Disorder Reduction Partnerships to ensure their response to hate crime against people with learning disabilities is mainstreamed within their response to hate crime overall.

National level actions for government departments

- 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.
- The Home Office will also work with DH on developing specific learning disability guidance for Crime and Disorder Reduction Partnerships, which include local authorities and the police.

⁸¹ *Safeguarding Adults: A Consultation on the Review of the ‘No Secrets’ Guidance*, DH, 2008



- DH will publish revised *No Secrets* guidance following consultation.
- The Crown Prosecution Service (CPS) has published its disability hate crime policy. It published the report on its first year's performance in its annual hate crime report in December 2008.⁸²
- The Office for Criminal Justice Reform will work with ACPO and Local Criminal Justice Boards to update national guidance and improve national standards and training to ensure vulnerable victims and witnesses are identified at the earliest possible stage and properly supported throughout the criminal justice process.

IV. Access to justice and redress

4.19 People with learning disabilities are less likely to make a complaint or seek legal redress if unfairly treated or if they experience poor practice because:

- systems and processes are often complicated, inaccessible and 'hidden';
- people with learning disabilities may lack confidence to speak out;
- people with learning disabilities may be more accepting of poor practice because experience of receiving poor quality services has given them low expectations; or
- people with learning disabilities may not be in a position to access the support they need and so strategies for extra access to support need to be devised.

82 *Hate Crime Report 2007–2008*, Crown Prosecution Service, 2008

4.20 The Care Standards Act 2000 requires all registered care homes and domiciliary care services to have a complaints procedure that is accessible and welcoming, and to make sure that people who use services and their families are fully aware of how to make a complaint. Other public services should also have an open complaints procedure. These should tell people what to do if a complaint is not resolved satisfactorily at a local level, and often there is a national body (e.g. the Care Quality Commission) that will receive complaints at a higher level and respond where necessary.

4.21 People can take legal action when they feel that their rights have been breached under the following acts (and others) which place a duty on public services:

- Human Rights Act 1998
- Disability Discrimination Act 2005
- Race Relations (Amendment) Act 2000
- Mental Capacity Act 2005 – Deprivation of Liberty Safeguards
- Mental Health Act 2007.

In some cases people can go to a tribunal to seek justice.

Making it happen locally and regionally – key recommended actions

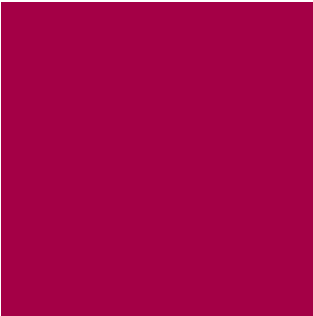
- Local services to develop accessible materials to help people with learning disabilities and their families understand their rights and how to complain.

National level actions for government departments

- DH will develop materials to help people with learning disabilities and their families understand their rights of redress and how to complain, and publish them on the revised *Valuing People Now* website.
- The CPS will respond to the consultation on a new policy on prosecuting crimes where people with learning disabilities are victims or witnesses published in December 2008.⁸³

⁸³ A consultation on the CPS Policy on prosecuting criminal cases involving people with mental health problems and/or learning disabilities as victims and witnesses, Crown Prosecution Service, 2008 (www.cps.gov.uk/consultations/mhld_index.html)

Chapter 5: Making it happen



I. Leadership and delivery structures

Overall policy objective: To put leadership, delivery and partnership structures in place that will make sure that the outcomes set out in this strategy are delivered.

- 5.1** *Valuing People* established a number of bodies and mechanisms to help implement its proposals but the biggest criticism of *Valuing People* has been the failure to deliver it in many areas. The top priority is to deliver the objectives in this strategy so that the *Valuing People* vision becomes a reality.
- 5.2** Key to delivering the vision for people with learning disabilities and their families will be the development of capacity and capability at local levels to design and commission the support services that people need to enable them to live independently and close to their families and friends. Partnership with people with learning disabilities and their families at local level will be crucial to this, and Learning Disability Partnership Boards have a vital role to play.
- 5.3** DH will develop tools and toolkits at a national, regional and local level to build capacity and capability locally to enable local systems and practices to develop to deliver key objectives for people with learning disabilities.
- 5.4** DH has appointed Deputy Regional Directors for Social Care and Partnerships in the Government Offices for the Regions to provide leadership and commission support to develop local capacity and capability. These Deputy Regional Directors will work with strategic health authorities and within the Government Office including with Regional Directors of Public Health, and Valuing People and personalisation regional leads to build capacity and capability locally to enable local systems and practices to develop to deliver key objectives.
- 5.5** Nationally and regionally, structures have been put in place to enable local services to change practice and improve support for people with learning disabilities through Joint Strategic Needs Assessments, Local Strategic Partnerships, Local Area Agreements, Joint Improvement Partnerships and Comprehensive Area Assessments. We will explore with the Care Quality Commission how, in carrying out its statutory functions, it can best support implementation.

5.6 Leadership for delivery at all levels will come from:

At a National level:

- the National Directors – will lead delivery including cross-government work, supported by a small team of national programme leads;
- the Learning Disability Programme Board, which is co-chaired by the Social Care Minister and the DH Director General for Social Care, Local Government and Care Partnerships, and will oversee the delivery of *Valuing People Now*. The board brings together key government departments and partners and will ensure the continued cross-government implementation of the strategy;
- the National Forum, which (via its nine regional forums) will continue to represent the voice of people with learning disabilities at national level, strengthening its contribution to policy making; and identifying how it will secure its future, and funding;
- the National Valuing Families Forum will bring the voices of family carers of people with learning disabilities to the national level through representation.

At a regional level:

- strategic health authorities, which will set the strategic direction and performance manage primary care trusts;
- Valuing People regional leads will report directly to the new Deputy Regional Directors for Social Care and Partnerships, making for strengthened policy and delivery leadership at regional level. These regional leads will support work to develop capacity and capability at local and regional level, particularly in relation to local Learning Disability Partnership Boards. With the Deputy Regional Directors, they will establish regional programme boards which will report on progress to the national Programme Board, set regional priorities, and agree regional support programmes including development bids for Regional Improvement and Efficiency Programme funding;
- the Learning Disability Development Fund (LDDF) is now paid directly to local authorities as part of the area-based grant to support them in delivering the key outcomes for people with learning disabilities within the National Indicator Set.



At a local level:

- the Valuing People team will develop tools to support local action to deliver transformation and support provision of robust data to inform local action, and enable partnership boards to benchmark progress;
- the National Directors and Valuing People team will target support on those areas that are underperforming and encourage good partnership boards to mentor poor performers. Directors of children and adult social services, PCT chief executives and local authority elected members have an important role to play. Third sector and independent sector providers will also be vital in delivering this strategy.

II. Partnership boards

'It is time for boards to make a noise and make sure that improving lives for people with learning difficulties is seen as a priority in the wider community.'

Speaking Up, Cambridge

5.7 *Valuing People* established local Learning Disability Partnership Boards to deliver at local level. Their impact has been variable. Two recent research reports⁸⁴ found that the effectiveness of boards was reliant on the commitment of their members, especially at senior officer level.

⁸⁴ *The Role and Effectiveness of Learning Disability Partnership Boards*, Rachel Fyson and Liz Fox, University of Nottingham, 2008 (www.mencap.org.uk) and *How well are Partnership Boards hearing the voices of People with Learning Difficulties and Family Carers?*, Speaking Up, 2007

While boards have improved the way in which they have involved people and their families overall, often they felt marginalised. In some places representation from other key agencies was poor, and only 1 in 3 boards set annual targets against which success could be measured.

- 5.8** One problem is that some partnership boards hardly exist outside the formal meeting. It would be more helpful for people to think of a range of local Learning Disability Partnerships, which exist all year around, with a Learning Disability Partnership Board meeting every few weeks to discuss and review these partnerships. Strong local partnerships depend on leadership from services, from self-advocates and from family carers. **Boards seen to be more effective and strong are usually led by the Director of Adult Social Care, with the authentic involvement of local self-advocacy and carer leaders.**
- 5.9** Local partnership boards will be expected to report regularly to the newly established regional programme boards; these regular reports must be agreed by the self-advocacy and family carer representatives on the board.

Making it happen locally and regionally – key recommended actions

- Learning Disability Partnership Boards will be supported by Valuing People regional leads to take their place at the centre of local delivery of the key objectives. This will mean building close links between partnership boards and the Joint Strategic Needs Assessment process, Local Strategic Partnerships and the Local Area Agreement, as well as local Overview and Scrutiny Committees.
- With support from the Valuing People regional leads, local Learning Disability Partnerships will review their board membership, processes of engagement and working practices with a view to ensuring that the board is properly constituted and led; consulted by statutory agencies; operating in line with good practice advice; and ensuring sufficient resources for the operation of the board. Directors of Adult Social Services and PCT Chief Executives have important leadership roles at local level.

- Deputy Regional Directors for Social Care and Partnerships and Valuing People regional leads will drive forward a programme of work to develop capacity and capability in localities to strengthen regional partnerships, and in particular will support the regional programme board to which they will provide an annual self-assessment of progress. Strategic Health Authorities and the Government Offices for the Regions have key roles to play within regional programme boards.

National level actions for government departments

- The National Directors and Valuing People team will invest in further strengthening of national structures that enable delivery of change.

III. Better commissioning

Overall policy objective: To ensure effective commissioning in a way that best supports the right outcomes for people with a learning disability and their families.

5.10 Effective partnership action will be essential for delivering the right outcomes for people with learning disabilities. Partnership boards will be integral to delivering success in commissioning across the full range of services needed by people with learning disabilities and their families.

5.11 A commissioning concordat is currently being developed across DH, CLG and DCSF which commits the three departments to improving and sharing their understanding of commissioning and the skills, knowledge and behaviours that effective commissioners need in order to design services and shape and secure better outcomes for individuals and communities.

5.12 The World Class Commissioning programme is DH's approach to improved commissioning. The programme aims to build the capability of local health commissioners to deliver better health and well-being for the population, improve health outcomes and reduce health inequalities.⁸⁵ A key aspect of this programme is for primary care trusts (PCTs) to lead the development of health and well-being in partnership with other local stakeholders.

5.13 Local authorities have a duty to prepare a Sustainable Community Strategy which sets out the strategic vision for an area together with a delivery plan, the Local Area Agreement. Local authorities and PCTs are required

85 www.dh.gov.uk/en/managingyourorganisation/commissioning/worldclasscommissioning/index.htm

to develop a Joint Strategic Needs Assessment (JSNA) which will inform the PCT's strategic plan and a range of other local commissioning plans overseen by the Learning Disability Partnership Board.

5.14 Local authorities have a lead responsibility:

- in commissioning services for people who have not taken direct control of their funding through Direct Payments and personal budgets; and
- for those who have Direct Payments or personal budgets, in helping to ensure the availability of appropriate support and a range of opportunities from which they can commission their own support in order to enable them to achieve their ambitions and aspirations.

5.15 NHS learning disabilities budgets and associated commissioning responsibility for all social care for adults with learning disabilities will transfer to local authorities by March 2010. This does *not* include resources for healthcare (whether general or specialist) or forensic/offender services, which will remain with PCTs. Guidance on this was issued to PCTs and local authorities in August 2008.⁸⁶ This change will allow the NHS to focus fully on its primary learning disability responsibility to ensure the delivery of equal access to good quality healthcare and well-being. But PCTs and local authorities will need to continue to work together to commission services to ensure good outcomes overall for people with learning disabilities who need support.

5.16 Spending on social care for adults with learning disabilities increased from approximately £1.5 billion in 1995/96 to approximately £3 billion in 2005/06 as a result of demographic changes, rising costs and improvements in services. The Comprehensive Spending Review settlement for local government recognises the demographic and other pressures facing the sector.

5.17 DH will explore how to improve information about the increasing demands on learning disability services in order to inform future spending decisions, taking account of:

- the role of strong regional and local partnerships to develop collaborative commissioning;
- the need for accurate data about the needs of people with learning disabilities;

- evidence from the InControl pilots which shows that individualised services, based on what people want, cost the same – if not less – than traditional services and that individualised services achieve better outcomes for people; and
- means to increase efficiency through systematic approaches to quality and costing services. A national tool to support this is being piloted.

5.18 Living locally, in your own community, is an important part of being a citizen. However, many people with learning disabilities have been sent to live far away from their home in residential homes or private hospitals. Best practice is that people should receive services locally and commissioners should develop systems to enable this, working closely with people with learning disabilities, family carers and service providers.

5.19 Where people are sent away from home, this makes it difficult to maintain social networks and friendships. In addition, this is overall an expensive way of giving people the support they need. Bringing people back to their home areas from such placements and developing local services to support people with learning disabilities to live independently is, therefore, a key goal. *Putting People First* emphasises that commissioning strategies should reflect the move to personalised services. The local authority transformation grant will enable local services to address this.

5.20 Evidence shows that commissioning appropriate local services can both deliver measurable improvements in quality of life and independence for people with learning disabilities, including those with complex needs or who may be described as challenging, and deliver savings in funding. There are good examples of action already well in hand to deliver this objective:

- In Hertfordshire the local authority and Hertfordshire Partnership NHS Foundation Trust sponsored the development of a new not-for-profit organisation to work in the county. With seed funding from an innovation grant over two years, Partners in Support was created in 2007 as a registered domiciliary care service provider. Working specifically with individuals who were seen to challenge services, Partners in Support have been developing individualised support solutions based on individuals' person centred plans, working closely with individuals and their families. As a result, people have been supported to move near to their families into accommodation of their choosing. Each person has their own team employed to work with

them, matching staff with similar interests and fully involving the individual and/or their family in the recruitment process.

- In Richmond, Surrey a smaller-scale project worked to bring three people home from long-established out-of-area placements. Working closely with the families and supported by an independent consultant, the local authority and health team developed individual care packages – for instance one has his own tenancy, with support, and is seeking work, another has moved from a large residential home into a house of her own with her own support team. Overall there have been considerable savings which have been reinvested in support services and measurably improved quality of life for the individuals concerned.

Making it happen locally and regionally – key recommended actions

- PCTs and local authorities agree locally on the NHS resources to be transferred to local government.
- Regional Valuing People leads will support local authorities and PCTs to develop robust commissioning processes based on the Joint Strategic Needs Assessment.

National level action by government departments

- Commissioning and funding for care services will be moved from the NHS to local government.
- DH will support work to further understand changes in demand for learning disability services.
- DH through the World Class Commissioning programme will provide further support to local commissioners by publishing a commissioning guide for the health and well-being of people with learning disabilities. This includes advice on approaches to the whole commissioning cycle as it relates to people with learning disabilities and offers some examples of best practice.
- A national toolkit for fair pricing of services will be launched in 2009.
- Valuing People regional leads will support delivery of the Mansell Report and the Local Services for Local People programme.

IV. Developing the workforce

5.21 Overall policy objective: The workforces across public services are given the appropriate support and training to equip them with the values, skills and knowledge to deliver the *Valuing People Now* priorities for all people with learning disabilities.

5.22 Implementing *Valuing People Now* has implications for workers across all areas of public services including those working in health, social care, education (including post-16 education), housing, transport, local government, employment agencies, Jobcentre Plus, the criminal justice system and the leisure industry, as well as in commissioned services. Government departments and the appropriate workforce organisations need to consider new ways of enabling a wide range of workers to develop the knowledge, skills and values to provide services to people with learning disabilities with respect and as equal citizens.

5.23 As more people with learning disabilities have direct payments or a personal budget, the workforce will need to change. Facilitation or brokerage may help people to make the best use of the money in their personal budget. People with learning disabilities and family carers who may support them, who decide to take the option of employing their own workers may need training to help them to be a good employer. People who choose to purchase their support from a provider may want to purchase different types of support from what is currently on offer. This will have significant implications across a range of service providers, and particularly for the adult social care workforce.

5.24 In December 2008 the Government published the *2020 Children and Young People's Workforce Strategy*.⁸⁷ This sets out the Government's vision that everyone who works with children and young people should be:

- **Ambitious** for every child and young person;
- **Excellent** in their practice;
- **Committed** to partnership and integrated working;
- **Respected** and valued as professionals.

5.25 DH is developing an Adult Social Care Workforce Strategy (*Putting People First – Working to Make it Happen*) which is due to be published in 2009. An interim statement, *Putting People First – Working to Make*

it Happen,⁸⁸ was published in June 2008. This sets out progress so far and the six strategic themes for the development of an Adult Social Care Workforce Strategy that could support the transformation of adult social care:

- recruitment, retention and career pathways;
- workforce development;
- workforce remodelling;
- leadership, management and commissioning skills;
- joint and integrated working; and
- regulation and quality improvement.

5.26 The workforce proposals relating to social care in *Valuing People Now* will need to be taken forward in the context of this wider Adult Social Care Workforce strategy.

5.27 Cross-government work on health, education, housing, transport, carers and criminal justice has workforce implications. Underpinning these new policies is a need for workforce plans including developing new training and qualifications where appropriate. Including people with learning disabilities and family carers in this planning and training is vital. The Learning Disability Awards Framework has raised the profile and value of learning disability specific training for a range of workers. Nationally accredited qualifications (such as NVQs) will be important in the future in promoting equal access to public services for people with learning disabilities.

5.28 To support the implementation of *Valuing People Now* the following priorities for workforce planning and development across all sectors and particularly the social care sector have been identified. The national workforce organisations, e.g. Skills for Care, have a key role to play within this:

- Preparing the workforce for the personalisation agenda, including:
 - strong local and national leadership and management of the change process;
 - all local authorities and provider organisations to offer a range of information and learning opportunities for staff;

88 *Putting People First – Working to Make it Happen*, Department of Health, 2008

- opportunities to learn from the early adopters of self-directed support about the workforce opportunities and challenges they have encountered to inform the change process and future provision;
- new learning disability-focused qualifications and career structures to provide a framework for change and to support workers in developing skills to support the transformation.
- Greater involvement of people with learning disabilities and family carers in all aspects of workforce planning and development.
- Promoting human rights and the *Valuing People Now* values in all professional courses and work-based training.
- Working with professional bodies, the relevant Sector Skills Councils and regulators to provide new national qualification and career structures to give all workers the knowledge and skills to deliver high-quality support and protect people from abuse.
- Developing the workforce to deliver support locally for the most excluded groups of people (people with complex needs, behaviour which challenges, autistic spectrum conditions, mental health needs, or people from black and minority ethnic communities), in line with the Mansell Report.

Martin's Story

Martin, a person with learning disabilities providing training about communication and hearing evidence from other people with a learning disability to JCHR. More details can be found at:

www.bild.org.uk/03consultancy_joint_committee_human_rights%20.htm



Making it happen locally and regionally – key recommended actions

- Regional Valuing People leads together with their regional workforce network will support partnership boards to continue their work in developing and implementing a local workforce plan.
- Regional Valuing People leads will work with regional and local bodies to address issues around workforce development including the benefits of involving people with learning disabilities and family carers in workforce planning and training and the need to adopt a human rights approach in workforce development in line with existing legislation.
- Support organisations and training providers to continue using the learning disability qualifications and NVQs for the induction and development of workers supporting people with learning disabilities.

National level actions for government departments

- The National Directors and the Valuing People team will drive forward a programme of work to set the environment for improvement including:
 - working with other government departments, public services and relevant workforce organisations and professional bodies to influence the way in which they approach the recruitment, training and development of their staff;



- bringing together all the learning about workforce issues relating to the personalisation agenda and supporting its wide dissemination to inform future workforce changes nationally and locally;
- supporting the implementation of the Adult Social Care Workforce Strategy in the sector;
- supporting the development and delivery of new knowledge sets and learning disability-focused qualifications and career pathways for workers supporting people with learning disabilities;
- working with the General Social Care Council (GSCC), Social Care Institute for Excellence (SCIE) and Skills for Care, we will explore how these national organisations can best support the workforce to deliver *Valuing People Now*;
- promoting the involvement of people with learning disabilities and family carers in all aspects of local, regional and national workforce planning and delivery;
- developing training materials where required for a range of different audiences to promote a greater understanding of human rights and a human rights approach.

V. Measuring performance and data collection

Overall policy objective: Learning disabilities will have a clear position in the new performance frameworks for the NHS and local authorities, and there will be a comprehensive range of data sets and reporting mechanisms.

5.29 Some current information and checking systems provide important information for the Government about learning disability. These include CSCI-collected data on expenditure on advocacy and the numbers of people taking up direct payments. Through inspections, regulators help to identify poor performance and enable commissioners and providers to address problems in delivering services.

5.30 But there are gaps in the data set – the NHS does not collect information on the health of people with learning disabilities; data collected by local authorities may no longer be relevant to modern learning disability services; and most data collected in the employment, education and housing sectors does not report specifically on learning disability. In taking forward this strategy, we will continue to explore how to improve information on the numbers and needs of people with learning

disabilities, in discussion with the Learning Disability Coalition and councils. This will enable better understanding of current and projected demands for this area and help to inform local needs assessments.

5.31 Nationally, there are frameworks which derive information to support the *Valuing People* vision including Public Service Agreements (PSAs). There are two relevant indicators specific to learning disabilities:

- PSA 16 (Increase the proportion of socially excluded adults in settled accommodation and employment, education or training)⁸⁹ includes two new national indicators to provide information on the social inclusion of people with learning disabilities:
 - the proportion of adults with learning disabilities known to councils in paid work;
 - the proportion of adults with learning disabilities known to councils in settled accommodation.
- PSA 15 (Address the disadvantage that individuals experience because of their gender, race, disability, age, sexual orientation, religion or belief).⁹⁰ Progress will be measured against the extent to which the Government closes the gaps in terms of independence and choice.

5.32 *The New Performance Framework for Local Authorities and Local Authority Partnerships*⁹¹ is the performance framework for Local Government, and sets out the mechanisms and performance indicators by which local authorities and their partners will be expected to deliver the national priorities described in the PSAs. Central to this framework is a new set of 196 national performance measures (known as the National Indicator Set), which form the basis for how Local Government reports on agreed priorities. These include the two indicator sets for people with learning disabilities under PSA 16 on employment and settled accommodation. All local authorities report on these indicators annually. They also select up to 35 of these indicators with their partners to prioritise locally within their Local Area Agreement (LAA). The LAA is set for three years and focuses activity on those indicators selected, which have specific stretch targets attached.

5.33 The NHS Operating Framework sets out the NHS's priorities. The two PSA indicators above are included in the NHS framework as measures

89 www.hm-treasury.gov.uk/d/pbr_csr07_psa16.pdf

90 www.hm-treasury.gov.uk/d/pbr_csr07_psa15.pdf

91 www.communities.gov.uk/publications/localgovernment/nationalindicator

for local action. This is because the NHS and DH have recognised the link between good health and social inclusion. This will mean meeting people's health needs in order to support them into work and to be able to live independently. As indicated in chapter 3, the Operating Framework for 2009/10 reinforces the importance of NHS organisations' response to the recommendations of the Independent Inquiry on access to healthcare.

- 5.34** From April 2009, the new Comprehensive Area Assessment (CAA) will provide the first holistic, independent assessment of the prospects for local areas and the quality of life for people living there. It will put the experience of citizens, people who use services and local taxpayers at the centre of the new local assessment framework, with a particular focus on the needs of those whose circumstances make them vulnerable, including people with learning disabilities. Reducing inequalities and discriminatory outcomes for all members of the community will be central to CAA. It will recognise the importance of effective local partnership working, the enhanced role of Sustainable Communities Strategies and Local Area Agreements and the importance of councils in leading and shaping the communities they serve. CAA will pay particular attention to how well people who need support are engaged with their local services. This will include the needs and interests of people who are at greater risk of lower quality of life outcomes. This will be reflected in how well matched services are to their needs and the means available to those people to influence decisions and service provision.
- 5.35** In 2006 the Government made a commitment to undertake a review of the health and social care performance frameworks as they relate to learning disability commissioning and services. 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.
- 5.36** The National Directors will continue to work with the health and social care regulatory bodies and other key bodies to explore ways of strengthening data collection and progress reporting.

Example of good practice

Regional health self-assessment and performance framework

In Yorkshire and Humber, the SHA Board, PCT Chief Executives and the Regional Association of Directors of Social Services approved a programme of work designed by independent consultant Jackie Sochocka and developed by the SHA and the Valuing People Regional Lead. The framework identifies four key health priority strands against which PCTs, Health Trusts and Learning Disability Partnership Boards have worked in partnership to assess and monitor performance across the region:

1. Resettlement and campus closure
2. Addressing health inequalities
3. Making sure people are safe
4. Continuing to achieve Valuing People objectives

The pilot was launched by Yorkshire and Humber region in October 2007 and is led by a Health Overview Group, chaired by a local PCT Chief Executive, with support from the SHA lead for Learning Disabilities and the Valuing People Lead.

The framework includes standards and key objectives, with criteria for assessment and indicative measures or sources of evidence drawn from key national reports, guidance and inquiries published in relation to improving healthcare for people with learning disabilities in recent years.

Following the success of this pilot, several other regions have signed up to using it in the future.

Making it happen locally and regionally – key recommended actions

- Valuing People regional leads will work to develop capacity and capability to enable robust collection of data locally to measure progress in delivering the strategy.

Key national level actions for government departments and regulatory bodies

- DH will continue to work to strengthen the performance framework and data collection methods.
- The National Directors will work with DH colleagues in developing the next version of the National Indicator Set (from 2011/12) to ensure that specific learning disability data can be collected.
- The National Learning Disability Programme Board will receive and respond to data about progress, via the regional boards, and the Valuing People team will collate this data, identify potential problem areas and agree with the regulatory bodies how best to respond.



The Delivery Plan

- 5.36** Delivering the outcomes for people with learning disabilities and their families relies on the development, implementation and monitoring of coherent and strategic plans at national, regional and local levels. 'Making it happen' is a task for central and local government, the NHS, housing providers, employment specialists, other statutory agencies, advocacy groups, and the community, voluntary and independent sectors. At every stage, locally and nationally, it is vital that people with learning disabilities and family carers are fully involved.
- 5.37** A comprehensive Delivery Plan is being published alongside *Valuing People Now*.⁹² This sets out the governance structures and actions, with timescales and responsibilities, necessary to support the implementation of *Valuing People Now*, nationally, regionally and locally. This will include the dissemination of a range of resources, including toolkits and guidance. In the spring, we will also produce a summary position statement setting out how the existing performance frameworks relate to provision of services for people with learning disabilities.
- 5.38** *Valuing People Now* is a restatement of an existing policy and much of its success relies on the implementation of other policies and legislation, as they relate to people with learning disabilities. What is needed to ensure change happens is action to:
- strengthen/improve existing practice;
 - ensure that all people with learning disabilities are fully included;
 - develop and deliver additional, enhanced, joined-up or more flexible services and structures; and
 - support, monitor and measure all of the above.
- 5.39** Many of the actions in this strategy are not about new initiatives. They are about ensuring compliance and best practice. To this end, there is no substantial additional funding to support the implementation of *Valuing People Now*.

92 *Valuing People Now: The Delivery Plan*. Department of Health (2009).

5.40 For each of the next three years, key priorities will be set in order to ensure that *Valuing People Now* is implemented and embedded in all areas. Progress will be reviewed at the end of each year and that review will inform the setting of priorities for the subsequent years. National and regional support for local implementation will focus on the annual priorities.

Key policy objectives for 2009–12

5.41 The following 15 policy objectives are taken from the preceding sections of the strategy.

Overall policy objective	Related legislation, policies, strategies or initiatives	Ways of measuring progress
All people with learning disabilities and their families will:		
benefit from <i>Valuing People Now</i>	Carers Strategy, DH 2007; Race Relations Act, 2005; Disability Discrimination Act, 2005; Children's Plan, DCSF, 2007; Children's Plan One Year On	JSNA, CAA Equalities Commission
have greater choice and control over their lives and have support to develop person centred plans	Independent Living Strategy, 2008; Putting People First; Health and Social Care Act, 2008; User-Led Organisations; Aiming High for Disabled Children, 2007	PSA 15

Overall policy objective	Related legislation, policies, strategies or initiatives	Ways of measuring progress
get the healthcare they need and the support they need to live healthy lives	DH response to Independent Inquiry, <i>Healthcare for All</i> , 2008; Disability Discrimination Act, 2005; <i>High Quality Care for All: NHS Next Stage Review</i> , DH 2008; Dementia Strategy (forthcoming); End of Life Care Strategy, DH 2008	NHS Operating Framework: vital signs indicator (health checks) Care Quality Commission
have an informed choice about where, and with whom, they live	<i>Communities in Control: real people, real power</i> , CLG 2008	PSA 16 accommodation
have a fulfilling life of their own, beyond services, that includes opportunities to work, study, and enjoy leisure and social activities	National Minimum Care Standards, 2000; Carers Strategy, DH 2008; Progression through Partnership, DfES 2006;	Care Quality Commission JSNA, CAA
be supported into paid work, including those with more complex needs	DWP Green Paper on Welfare Reform, 2008 DWP consultation on disability employment services, 2008 Employment Strategy (forthcoming)	PSA 16 paid work
have the choice to have relationships, become parents and continue to be parents, and be supported to do so	Human Rights Act, 1998; Independent Living Strategy, 2008	

Overall policy objective	Related legislation, policies, strategies or initiatives	Ways of measuring progress
be treated as equal citizens in society and supported to enact their rights and fulfil their responsibilities	Human Rights Act 1998; Joint Committee on Human Rights, <i>A Life Like Any Other?</i> 2008; Independent Living Strategy, 2008; Disability Discrimination Act 2005	Equalities Commission
have the opportunity to speak up and be heard about what they want from their lives – the big decisions and the everyday choices. If they need support to do this, they should be able to get it	Valuing People Central Advocacy Programme Fund; Independent Living Strategy, ODI 2008	
be able to use public transport safely and easily and feel confident about doing so	Disability Discrimination Act, 2005; <i>Inclusive Mobility</i> , DfT 2005	
be able to live in safe environments and feel confident that their right to live in safety is upheld by the criminal justice system	Disability Discrimination Act, 2005; Race Relations (Amendment) Act, 2000; No Secrets (Safeguarding) Guidance, DH (to be revised)	
For services		

Overall policy objective	Related legislation, policies, strategies or initiatives	Ways of measuring progress
Leadership, delivery and partnership structures are in place that will make sure the outcomes set out in this strategy are delivered		
Effective commissioning in a way that best supports the right outcomes for people with learning disabilities and their families is ensured	World Class Commissioning programme (DH)	JSNA, CAA
The workforces across services are given the appropriate support and training to equip them with the values, skills and knowledge to deliver the <i>Valuing People Now</i> priorities for all people with learning disabilities	Adult Social Care Workforce Strategy (DH, to be published)	
Learning disabilities will have a clear position in the new performance frameworks for the NHS and local authorities, and there will be a comprehensive range of data sets and reporting mechanisms	Learning Disability Performance Framework Position Statement (DH, to be published); 2020 Children’s and Young People’s Workforce Strategy, DCSF 2008	NHS Operating Framework HCC and CSCI, CQC regulatory frameworks JSNA, CAA

Abbreviations and glossary



ACPO: Association of Chief Police Officers (ACPO)

ADASS: Association of Directors of Adult Social Services

Aiming High for Disabled Children

This is the transformation programme for disabled children's services.

BME: Black and Minority Ethnic

CLG: Department for Communities and Local Government

Children's Plan

The Children's Plan puts the needs of families, children and young people at the centre of everything DCSF does.

Children's Plan One Year On

What has been achieved during the first 12 months of the Children's Plan.

CQC: Care Quality Commission

CSED: Care Services Efficiency Delivery helps councils to identify and develop more efficient ways of delivering adult social care.

CSCI: Commission for Social Care Inspection

Comprehensive Area Assessment (CAA)

From April 2009 CAAs will replace the Comprehensive Performance Assessments used by the Audit Commission. CAAs will provide the first independent assessment of the prospects for local areas and the quality of life for people living there. It will assess and report on how well public money is spent and ensure that local public bodies are accountable for their quality and impact.

Crime and Disorder Reduction Partnership/Community Safety Partnership

Statutory bodies – the police, police and local authorities, fire and rescue authorities, primary care trusts – with a statutory duty to work with local agencies and other organisations to develop and implement strategies to tackle crime and disorder.

CSIP: Care Services Improvement Partnership (part of DH)

DCSF: Department for Children, Schools and Families

DfT: Department for Transport

DH: Department of Health

DIUS: Department for Innovation, Universities and Skills

DWP: Department for Work and Pensions

Direct Payments

These are cash payments given to people with learning disabilities in lieu of the community care services they have been assessed as needing. They are intended to give people greater choice in their care. The payment must be sufficient to enable the person to purchase services to meet their needs and must be spent on services that he or she needs. Recipients of direct payments take on all the responsibilities of an employer-payroll, meeting the minimum wage and other legislative requirements and establishing contracts of employment. [See also individual and personal budgets.]

Directed Enhanced Service (DES)

In primary care an 'enhanced service' is one not provided through essential or additional services. They offer a key tool to help primary care trusts (PCTs) reduce demand on secondary care, with their main purpose being to provide an opportunity to expand and develop primary care. 'Directed enhanced service' is one that must be provided by the PCT for its population.



Disability Equality Duty (DED)

A duty introduced by the Disability Discrimination Act 2005 which requires the public sector to promote equality of opportunity for disabled people, and public servants to consider the impact of their work on disabled people and take action to tackle inequality.

Disability Equality Scheme

Public authorities are required to produce and implement Disability Equality Schemes. Statutory regulations prescribe how such schemes are to be drawn up.

DRC: Disability Rights Commission

DRD: Deputy Regional Director of Social Care and Partnerships

Exemplar Sites

Part of the programme supporting primary care trusts (PCTs) with the rollout of practice based commissioning. An exemplar site consists of a PCT and up to five GP practices.

FE: Further Education

GO: Government Office (for the Regions)

GSCC: General Social Care Council

HO: Home Office

IDeA: Improvement and Development Agency

Individual Budgets

These were piloted in 2006 and involved bringing together six funding streams: social care, Supporting People, Disabled Facilities Grant, Independent Living Funds, Access to Work and community equipment services. (See also Direct Payments and Personal Budgets.)

Joint Improvement Partnership (JIP)

A partnership of organisations involved in improving services within social care. Partners are ADASS, CSIP, CSCI, the English Community Care Association, IDeA, LGA, the NHS Institute for Innovation and Improvement, Skills for Care and SCIE.

Joint Strategic Needs Assessment (JSNA)

The Local Government and Public Involvement in Health Act 2007 places a duty on local authorities and PCTs to undertake these assessments. This is a process that will identify current and future health and well-being needs of the local population, informing the priorities and targets set by Local Area Agreements and leading to agreed commissioning priorities that will improve outcomes and reduce health inequalities.

Learning Disability Partnership

These are ways of working at a local level which are broader than Learning Disability Partnership Boards.

Learning Disability Partnership Boards

These were set up under Valuing People (2001) to promote stronger local partnerships. Members include senior leaders in local authorities, PCTs and other local services, as well as third sector organisations, people with learning disabilities and families and carers.

Local Area Agreement (LAA)

These set out the priorities for a local area in a three-year agreement between central government and a local area (the local authority and the Local Strategic Partnership (see below) and other key partners at local level). They simplify some central funding, help join up public services more effectively and allow greater flexibility for local solutions to local circumstances.

LDDF: Learning Disability Development Fund

LGA: Local Government Association

Local Involvement Network (LINK)

LINKs are set up to help people influence or change the way their health or social care services are delivered. They are made up of individuals and community groups who work together to improve local services. It is their job to find out what people like and dislike about local services and work with the people who plan and run them to help make them better.

Local Strategic Partnership (LSP)

These are non-statutory bodies that bring together the different parts of the public, private, voluntary and community sectors working at local level. The lead player in an LSP is the local authority and other players will include the police and PCT.

MHAC: Mental Health Act Commission

MoJ: Ministry of Justice

National Advisory Group on Learning Disability and Ethnicity

The Foundation for People with Learning Disabilities co-ordinates this advisory group which has a remit to advise the Government on the changes that would help people with learning disabilities from black and minority ethnic groups. It focuses on policy development and works closely with other organisations.



NVFF: National Valuing Families Forum

ODI: Office for Disability Issues

OND: Office of the National Directors

OTS: Office of the Third Sector

Overview and Scrutiny Committee

This monitors the activities of a local authority and local NHS bodies.

PCT: Primary Care Trust

PALS

Patient Advice Liaison Services (PALS). These provide information, advice and support to help patients, families and carers.

Personal Budgets

These are an allocation of funding given to users of community care services after an assessment at a level that should be enough to meet their assessed needs. People can take them either as direct payments (see above) or – while choosing how their care needs are met and by whom – leave local authorities with the responsibility to commission the services. Or they can have some combination of the two.

Public Health Observatory (PHO)

A resource for enquiry, an observatory searches for and compiles information and data sets on the nation's health and, from them, distils the knowledge to guide its improvement.

Public Service Agreement (PSA)

These are agreements between different parts of government that are underpinned by a single delivery agreement shared across contributing departments and developed in discussion with delivery partners and frontline workers

Race for Justice

This is a cross-government programme to improve the way in which hate crime is investigated and prosecuted. It is led by the Attorney General and seeks to coordinate the activity of all Criminal Justice Partners and stakeholders to ensure consistent service. It considers the response from the initial police call handling through to the court hearing.

SCIE: Social Care Institute for Excellence

SEN: Special Educational Needs

SfC: Skills for Care

SHA: Strategic Health Authority

ULO: User-Led Organisation

These are local organisations run and controlled by disabled people, carers and other people who use support. They aim to promote independent living and provide services such as information and advice, advocacy and peer support and support in using Direct Payments and individual budgets.

Vital Signs Indicators

These were introduced in the NHS Operating Framework for 2008/09 as a new approach to planning and managing priorities nationally and locally. There are five categories: cleanliness and healthcare associated infections; access to personalised and effective care; improving health and reducing health inequalities; reputation, satisfaction and confidence in the NHS; and finance. Primary care trusts are expected to choose – in consultation with local partners – which vital signs to prioritise locally.

World Class Commissioning

A Department of Health programme designed to transform the way in which health and care services are commissioned. It has four key elements: vision for world class commissioning; a set of world class commissioning competences; an assurance system; and a support and development framework.



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