



# Valuing People **Now**

From Progress to Transformation

## DH INFORMATION READER BOX

<b>Policy</b> HR / Workforce Management Planning / Clinical	Estates Commissioning IM & T Finance Social Care / Partnership Working
<b>Document Purpose</b> Consultation/Discussion	
<b>ROCR Ref:</b>	<b>Gateway Ref:</b> 8854
<b>Title</b> Valuing People Now: From Progress to Transformation	
<b>Author</b> Social Care, Local Government and Care Partnerships Directorate, DH	
<b>Publication Date</b> 04 Dec 2007	
<b>Target Audience</b> PCT CEs, NHS Trust CEs, SHA CEs, Care Trust CEs, Foundation Trust CEs, Local Authority CEs, Directors of Adult SSs	
<b>Circulation List</b> Medical Directors, Directors of Nursing, NHS Trust Board Chairs, Directors of HR, Directors of Finance, Allied Health Professionals, GPs, Voluntary Organisations/NDPBs	
<b>Description</b> Valuing People' set out the Government's vision for people with a learning disability across a range of services based on the four key principles of rights, independence, choice and inclusion. 'Valuing People Now' seeks people's views on the priorities for the learning disability agenda over the next three years.	
<b>Cross Ref</b> Valuing People (2001)	
<b>Superseded Docs</b> N/A	
<b>Action Required</b> Consultation	
<b>Timing</b> By 11 Mar 2008	
<b>Contact Details</b> Wendy Brown Rm 120, Department of Health Wellington House 133 - 155 Waterloo Rd, London SE1 8UG 0207 972 4145 <a href="http://www.dh.gov.uk/en/Policyandguidance/Socialcare/Deliveringadultsocialcare/Learningdisabilities/index.htm">http://www.dh.gov.uk/en/Policyandguidance/Socialcare/Deliveringadultsocialcare/Learningdisabilities/index.htm</a>	
<b>For Recipient's Use</b>	

## CONTENTS

Consultation process	4
Foreword from the Secretary of State for Health	6
Part 1: Introduction and Executive Summary	7
Introduction	8
Executive Summary	10
Part 2: The Big Priorities	17
Priorities For <i>Valuing People Now</i>	18
Personalisation	19
What People Do During the Day (And Evening And Weekends)	22
Better Health	28
Improving People's Housing Situation	33
Part 3: The Wider Agenda	38
Advocacy And Rights	39
Partnership With Families	42
Including Everyone	44
People As Local Citizens	50
Making The Transition to Adulthood A Positive Experience	56
Improving The Workforce	57
Part 4: The Biggest Priority – Making It Happen	61
Providing The Right National And Local Leadership And Support	62
Better Commissioning	66
Getting Better At Checking How We Are Doing	71
Part 5: The Consultation	74
What Do You Think About <i>Valuing People Now</i>	74

## **The Consultation Process**

### Criteria for consultation

This consultation follows the ‘Cabinet Office Code of Practice’, in particular we aim to:

- consult widely throughout the process, allowing a minimum of 12 weeks for written consultation at least once during the development of the code of practice;
- be clear about what our proposals are, who may be affected, what questions we want to ask and the timescale for responses;
- ensure that our consultation is clear, concise and widely accessible;
- ensure that we provide feedback regarding the responses received and how the consultation process influenced the code of practice;
- monitor our effectiveness at consultation including through the use of a designated consultation co-ordinator; and
- ensure our consultation follows better regulation best practice, including carrying out a Regulatory Impact Assessment if appropriate.

The full text of the code of practice is on the Cabinet Office website at:

<http://bre.berr.gov.uk/regulation/consultation/code/index.asp>

### **Comments on the consultation process itself**

If you have concerns or comments which you would like to make relating specifically to the consultation process itself please

contact            Consultations Coordinator  
                         Department of Health  
                         2N16, Quarry House  
                         Leeds  
                         LS2 7UE

e-mail             Mb-dh-consultations-coordinator@dh.gsi.gov.uk

**Please do not send consultation responses to this address.**

### Confidentiality of information

Information provided in response to this consultation, including personal information, may be published or disclosed in accordance with the access to information regimes (these are primarily the Freedom of Information Act 2000 (FOIA), the Data Protection Act 1998 (DPA) and the Environmental Information Regulations 2004).

If you want the information that you provide to be treated as confidential, please be aware that, under the FOIA, there is a statutory Code of Practice with which public authorities must comply and which deals, amongst other things, with obligations of confidence. In view of this it would be helpful if you could explain to us why you regard the information you have provided as confidential. If we receive a request for disclosure of the information we will take full account of your explanation, but we cannot give an assurance that confidentiality can be maintained in all circumstances. An

automatic confidentiality disclaimer generated by your IT system will not, of itself, be regarded as binding on the Department.

The Department will process your personal data in accordance with the DPA and in most circumstances this will mean that your personal data will not be disclosed to third parties.

## Foreword from the Secretary of State for Health

When *Valuing People* was published in 2001 it was a significant achievement as the first white paper on learning disabilities in thirty years. The vision and expectations in *Valuing People* set out what the Government's commitments were to improving the life chances of people with learning disabilities – but what was so important about its publication was that it was a vision that was welcomed and supported by people with learning disabilities, their families, and professional in all sectors.

Six years on I, and many others, believe that what we said should be achieved in *Valuing People* was right. We have seen some good progress in some areas but unfortunately for far too many people with learning disabilities, much has remained unchanged. *Valuing People: The Story So Far* published in 2005 set out what had been achieved and in what areas much more progress was required. Two years on from that report, we are still faced with the same challenges, particularly in ensuring that people with learning disabilities can access mainstream services for health, housing, education and employment – the things that ensure equality of citizenship.

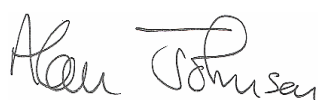
I know that there are many committed staff, carers and self-advocates who are determined, rightly so, not to rest until we have achieved independent living for the vast majority, if not all people with learning disabilities. That is why the Government is determined to reinvigorate the agenda.

*Valuing People Now: From Progress to Transformation* sets out the priorities for the provision of services for people with learning disabilities over the years 2008-2011. It stands by the commitments made in 2001 and considers them in the context of what has happened over the last six years in terms of national policy, local delivery and any new issues that we need to address. The main priorities that *Valuing People Now* has focussed on are personalisation, what people do during the day, better health, access to housing and making sure that change happens. We have also made sure that we have covered other issues that we know are important such as hate crime and relationships.

*Valuing People Now* has been developed based on the views of a range of stakeholders. We hope that we have got it right and we are consulting with you as we want to hear your views.

There is no question that it is a human rights issue that all people with learning disabilities have the choices and control over their lives that so many of us take for granted – a life like any other. I am determined that we will work together across government, across services and most importantly with people with learning disabilities, to achieve this goal.

Our mission is to move from progress to transformation in the every day experience of people with learning disabilities and their families.



**Rt Hon Alan Johnson MP**  
**Secretary of State for Health**

# Part One

## Introduction and Executive Summary

## 1 Introduction

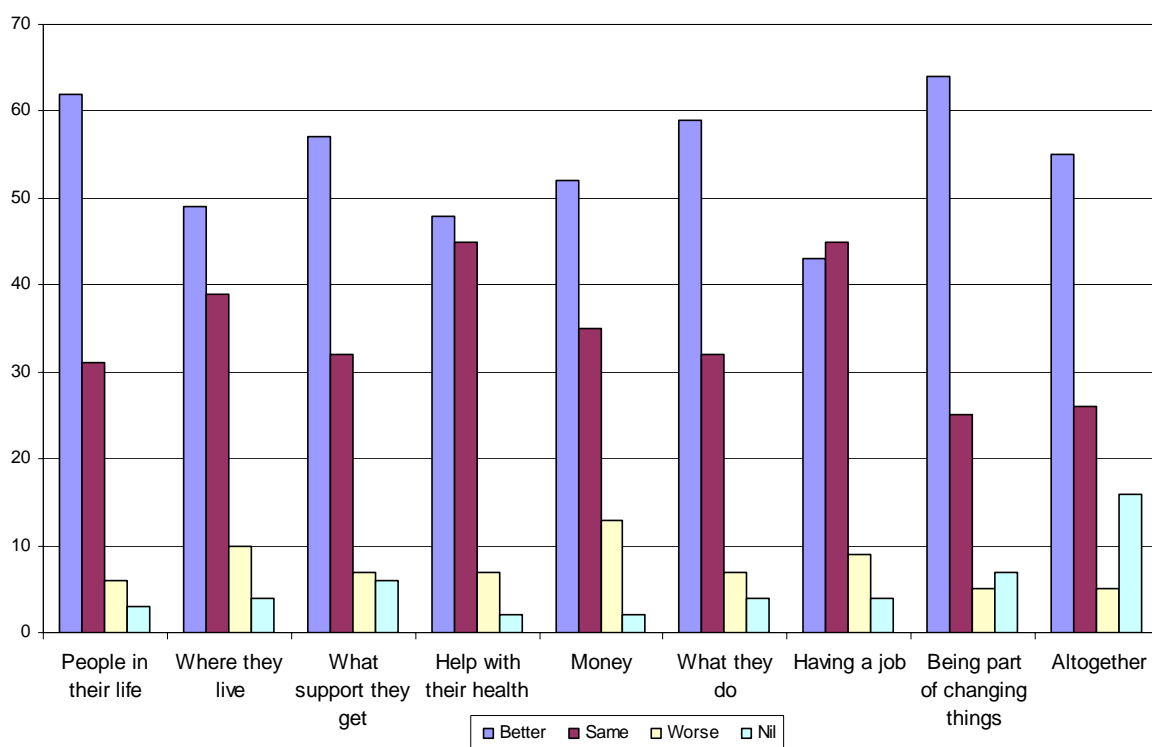
- 1.1 In 2001, the Government published *Valuing People: A New Strategy for Learning Disability for the 21<sup>st</sup> Century*. It was the first major government policy statement about learning disabilities for thirty years. Importantly, *Valuing People* was a cross-government policy – with a foreword by the Prime Minister. It was not just about health and social care, but also covered jobs, education, housing and other areas of government policy. The vision was based on four main principles of:
- legal and civil rights;
  - independence;
  - choice; and
  - inclusion.
- 1.2 *Valuing People* was widely welcomed by people with learning disabilities, their families and people working in the learning disability field. Many said it was a groundbreaking policy because it stressed how people with learning disabilities are, above all else, people and citizens. It said that the role of public services is to help people, no matter how complex their disabilities, to live full and equal lives in their local communities.
- 1.3 Since 2001, other Government policies have said similar things and have helped to take forward the *Valuing People* vision. For example:
- *Improving the Life Chances of Disabled People* – with its focus on independent living. (Defined as people having choice and control over the support they need to live their lives they want.);
  - *Our Health, Our Care, Our Say* – which confirmed the Government's commitment to individual budget pilots – giving people real control over their lives and services;
  - by amending the Disability Discrimination Act 1995 (DDA) in 2004 and 2005, rights for disabled people have been substantially improved and extended - for example in relation to employment.
- 1.4 In addition, the Human Rights Act (1998) has influenced the policies and principles of *Valuing People*.
- 1.5 Six years on, some people's lives have changed for the better, but for others little has changed. In part this is because changing the lives of people with learning disabilities involves changing the attitudes of all of society towards disabled people – and that takes time. In part it is because, despite good progress in many areas, not everyone has taken forward the *Valuing People* vision as quickly and as positively as we had hoped.
- 1.6 In 2005, around three thousand people contributed to the National Director's review of *Valuing People - The Story So Far*. This described good progress in some areas:
- people are being listened to more – both about their individual lives and in service planning;
  - person centred planning, done properly, makes a difference to people's lives;
  - the Supporting People programme has helped many people to live independently;
  - direct payments are helping to change people's lives;



- organisations are working together better at a local level.

1.7 Overall people said that things were improving. People were asked whether their lives, or those of people they knew, were getting better in different ways. Figure 1 shows that people were generally very positive about how things have improved since *Valuing People*. However, in some areas (e.g. paid work and access to good quality healthcare), progress has been disappointing. There is evidence that progress for some people - such as those with high support needs and from minority ethnic communities - has been less than for others.

Fig. 1 ‘Story So Far’ Consultation



- 1.8 A short summary of progress so far with *Valuing People* is:
- good progress in many areas but disappointing change in others;
  - getting some mainstream services to be properly inclusive of people with learning disabilities has been difficult;
  - too many people and organisations have failed to deliver on the policy promises;
  - where change has happened, some people now feel it is getting difficult to move onto the next stage of change.
- 1.9 Government has therefore decided that it is time to ‘refresh’ the *Valuing People* policy. This document - *Valuing People Now: From Progress to Transformation* - is a draft of how government intends doing that from 2008 to 2011. It responds to what people have told us over the last six years about what is working and what is proving difficult to change.

- 1.10 *Valuing People Now* should be considered alongside other government policies that affect the lives of people with learning disabilities. In particular, the independent living strategy, which is shortly to be published from the Office of Disability Issues.
- 1.11 *Valuing People Now* does not repeat all the evidence and arguments behind why the policy says what it does. These can be found in places such as *The Story So Far*, *Our Health Our Care, Our Say*, *Improving the Life Chances of Disabled People* and *Valuing People* itself.<sup>1</sup> *Valuing People Now* is concerned with describing the action that is required in order to make good on existing policy commitments.
- 1.12 We would welcome your comments on what *Valuing People Now* says by 11 March 2008. Details of how to comment are contained on page 74. A final document will then be produced by summer 2008.

## 2. **Executive Summary**

### 2.1 *Overview*

- 2.1.1 *Valuing People* aimed to achieve equality of citizenship for people with learning disabilities. Its focus on promoting advocacy, person centred planning and partnership working to achieve change has led to improved lives for many people with learning disabilities. With only one long stay hospital still to close, thousands of people living in their own homes with help from Supporting People and over 5,000 people using direct payments, some people's lives have changed dramatically. However, for many people little has changed and delivery has been patchy across the country.
- 2.1.2 In response to this, *Valuing People Now* sets out the next steps for the *Valuing People* policy and its delivery. It describes the direction of travel and delivery priorities for the next three years. The aim is to support people with learning disabilities to live an ordinary life in the community alongside their fellow citizens as described by human rights legislation and the Disability Discrimination Act. To help achieve this, *Valuing People Now* sets out policies and actions aimed at making sure that people get real choice and control over the services and support they need and that mainstream public services become more inclusive of people with learning disabilities.
- 2.1.3 *Valuing People Now* does not cover children with a learning disability because other policies (including *Aiming High For Disabled Children*) are already taking new action forward for children.

---

<sup>1</sup> 'The Story So Far.... *Valuing People A New Strategy for Learning Disability for the 21<sup>st</sup> Century*,' 2005, Valuing People Support Team:  
[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_4107054](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4107054)

'Our Health, Our Care, Our Say' White Paper,' 2006, Department of Health  
[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_4127453](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4127453)

'Improving the Life Chances of Disabled People,' 2005, Cabinet Office:  
<http://www.cabinetoffice.gov.uk/upload/assets/www.cabinetoffice.gov.uk/strategy/disability.pdf>

2.1.4 Perhaps the biggest challenge is making sure that the *Valuing People* policy is delivered across all of England. To help do this, *Valuing People Now* identifies five big priorities that government wishes local people (and government itself) to concentrate on. These priorities are what people themselves and their families tell us will have the greatest impact on their lives.

2.1.5 The main priorities for 2008 to 2011 are:

- **Personalisation** – so that people having real choice and control over their lives and services;
- **What people do during the day** (and evenings and weekends) - helping people to be properly included in their communities, with a particular focus on paid work;
- **Better health** - ensuring that the NHS provides full and equal access to good quality healthcare;
- **Access to housing** - housing that people want and need with a particular emphasis on home ownership and tenancies;
- **Making sure that change happens** and the policy is delivered - including making Partnership Boards more effective.

2.1.6 Sections 2.2 and 2.3 below summarise the main actions described in *Valuing People Now*. Knowing that we are achieving these changes is essential. Each section from Section 5 onwards outlines how we will know whether people's lives are changing for the better. Central to this will be:

- improving the ways in which data is collected and reported, both locally and nationally;
- listening to the voices of families and carers;
- giving a more central role to learning disability partnership boards as the voice of local stakeholders;
- checking that lives are improving for some of the most excluded people, for example people with complex disabilities and those from minority ethnic communities.

## 2.2 *Big Priorities*

### *Personalisation*

2.2.1 Too many people are still receiving traditional services rather than being supported to live the life they want. People having the choice and control over their own lives and services is the starting point for *Valuing People Now*. Action will include:

- government continuing with plans for individual budgets and giving more people control over their lives and services;
- a renewed focus on person centred planning;
- work continuing to help more people have a direct payment.

### *What People Do During The Day*

2.2.2 Joined up working between adult social services, the employment and education sectors should be at the centre of people getting better lives. To address the problem of people going to traditional day centres rather than getting a job and education and a life, action will include:

- moving away from the concept of day services modernisation and instead having the policy objective of supporting people to live the lives that they want as equal citizens in their communities - in other words social inclusion;
- using outcomes from person centred plans to design new opportunities and supports for people, with paid work at the centre of this;
- a cross government Getting a Life programme to bring together funding and assessment systems for young people going through transition, with the aim of people getting a job, an education and a social life in the way they want;
- a review of government disability employment services with the aim of increasing the number of people with learning disabilities in paid work;
- a five-year 'Progression Through Partnership' programme to help make further education better meet the needs of learners with learning disabilities;
- government prioritisation of employment through the socially excluded adults PSA.

#### *Better health*

2.2.3 Several recent reports have raised concerns of how people with learning disabilities access healthcare. Actions to address this will include:

- initiatives to ensure the NHS meets its legal obligations in relation to human rights and disability discrimination;
- a new primary care service framework to support PCTs in commissioning comprehensive health checks and better primary care access for people with learning disabilities;
- issuing new good practice guidance on health action planning;
- local action by PCTs and NHS trusts to ensure that acute healthcare is properly meeting the needs of people with learning disabilities;
- the Department of Health responding to the independent inquiry into the healthcare of people with learning disabilities, chaired by Sir Jonathan Michael, when it reports to the Secretary of State later this year;
- good practice guidance on specialist learning disability health services and local action plans to improve bed-based learning disability services following the Healthcare Commissions audit of NHS and private sector services;
- clear statements in the forthcoming NHS operating framework about delivery in relation to learning disability.

#### *Improving people's housing situation*

2.2.4 People with learning disabilities should have more choice and control over where and how they live. Action to help this happen will include:

- a joint Department for Communities and Local Government and Department of Health programme to promote the inclusion of people with learning disabilities in mainstream housing initiatives;
- an increased focus on access to home ownership and housing with assured tenancies;
- funding to support the closure of NHS campuses;
- government employment of housing through the socially excluded adults PSA;
- support providers focusing on the social inclusion agenda described in *Valuing People Now*

## 2.3 The Wider Agenda

### *Advocacy and rights*

2.3.1 The *Valuing People* commitment of ‘Nothing About Us Without Us’, remains at the heart of *Valuing People Now*. Action to ensure that people's voices properly heard and their rights are respected includes:

- a new learning disability advocacy development programme - including leadership development;
- the development of user led organisations in each locality, being fully inclusive of people with learning disabilities, as recommended in *Improving the Life Chances for Disabled People*;
- a full government response to Parliament's Joint Committee on Human Rights inquiry into the rights of adults with learning disabilities when its report is published.

### *Partnership with families*

2.3.2 Family carers are essential long-term partners in achieving positive change for people with learning disabilities. Action to help make this happen will include:

- a Standing Commission on carers to ensure the voice of carers is heard by government;
- updating and extending the Prime Minister's strategy of carers;
- more practical support to carers; including the creation of an expert carers programme, a national information service/helpline for carers, and support for short term home-based care;
- support for developing family leadership as part of the *Valuing People* delivery programme;

### *Including everyone*

2.3.3 There is concern that changes so far have excluded some groups of people. *Valuing People* will only be a success once it is working for everyone. Action to help this happen includes:

- local planning to deliver *Valuing People Now* starting with people with the most complex support needs, with the principle of developing additional services and supports, rather than separate ones;
- full compliance with race relations legislation leading to proper information that helps develop culturally appropriate services for all people with learning disabilities;
- use of the government's advice note on people with autism to ensure people do not fall between different local services;
- a programme of work to improve the skills of the criminal justice system in working with people with learning disabilities.

### *People as Local Citizens*

2.3.4 People want to be full members in their local community and so action outside traditional learning disability services is important. This will include:

- local and national action to stop hate crime against people with learning disabilities. This will include good practice guidance from the Home Office and the Department of Health;
- the Department for Transport working with the *Valuing People* delivery programme to ensure transport initiatives are inclusive of people with learning

disabilities. Local learning disability partnerships getting involved with the development of local transport plans so this happens at a local level;

- a focus on relationships when planning with people about their own lives, including personal and sexual relationships;
- support to parents with a learning disability and their children as described in the existing good practice guidance and the inclusion of parents with a learning disability in new parenting initiatives supported by the Department for Children Schools and Families.

#### *Transition to adulthood*

2.3.5 As young people with a learning disability move into adulthood, they should have access to the same life opportunities as everyone else. Action to help achieve this will include:

- a £19 million transition support programme, part of which will be used to promote person centred approaches in transition;
- continued support for the person centred transitions national initiative;
- a focus on young people in transition for all aspects of *Valuing People Now* i.e. jobs, housing, individual budgets etc.

#### *Improving The Workforce*

2.3.6 New ways of working for staff who support people with learning disability have to underpin the changes from *Valuing People Now*. This will include:

- the adult social care workforce strategy board taking responsibility for overseeing the delivery of the learning disability workforce planning and development programme;
- Skills for Care leading national and local action to increase take-up of the learning disability qualification and sharing leadership of regional learning disability workforce networks;
- local training to ensure a focus on skills to support choice, control and social inclusion.

### 2.4 The Major Priority - Making It Happen

2.4.1 The biggest challenge facing *Valuing People* is that of making sure that the whole policy is delivered so that all people with learning disabilities benefit from the changes. Action to ensure this happens is therefore at the centre of *Valuing People Now*. In addition to the above actions, specific actions around delivery are set out below.

#### *Local and National Leadership and Support*

2.4.2 Strong local and national leadership is required for the next three years and beyond. To help this happen:

- local learning disability partnerships will continue, with an expectation that they review board meetings to reflect best practice across the country. Government will explore how to increase the statutory requirement on public bodies to consult and work with partnership boards;
- the Learning Disability Development Fund (LDDF) will continue, being paid directly to local authorities to support delivering the outcomes in the National Indicator Set for people with learning disabilities. The old long stay (OLS) census will come to an end;

- there will be continuing support for the National Forum of People with Learning Disabilities and the Learning Disability Task Force;
- the *Valuing People* Support Team will be redesigned to meet the changing agenda - with a twin focus on delivering the main national priorities and supporting local people to develop the skills to make the changes themselves.

#### *Better commissioning*

2.4.3 In order to help improve commissioning, action will include:

- funding for learning disability social care services will transfer from the NHS to local government. This means that local authorities, who are the lead commissioning authority for learning disability services, will have direct access to the resources they need to improve services;
- work to fully assess the impact of the increasing numbers of people with learning disabilities on demand for, and therefore the cost of, services;
- action to ensure that the only reason a person with a learning disability is an inpatient in an NHS or private sector hospital bed is because they are receiving an active programme of assessment or treatment prior to moving back home to their local community;
- re-issuing the Mansell report on people who challenge services, with a support programme to help its implementation.

#### *Getting better at checking how we are doing*

2.4.4 If *Valuing People Now* is to be delivered, we need to know what progress we are making and encourage managers to do things better. To help this happen, action will include:

- two new cross government performance indicators on employment and housing;
- a review of the NHS and adult social care performance framework in order to improve how we monitor learning disability services;
- joint strategic needs assessments including accurate information about the lives of people with learning disabilities (in order to comply with disability discrimination legislation);
- encouraging local learning disability partnerships to establish their own outcome indicators and publicly report on progress with them.

### **3. Children with a Learning Disability**

3.1 *Valuing People* covered policy about children with a learning disability as well as adults. Shortly afterwards, Government produced several other policies about children which became the focus of change for children with a learning disability. Those policies have continued to develop and so there is less need for this 'renewal' of *Valuing People* to also cover children (though transition to adulthood is covered in paragraph 13).

3.2 Getting the right educational support in the right setting is key to helping children with learning disabilities reach their potential and be part of society. The 2001 Special Educational Needs (SEN) and Disability Act strengthened parents' rights to have their child educated in a mainstream school if they wish. It gave schools and local authorities a duty to plan to increase schools' accessibility, both in terms of premises and the curriculum.

3.3 In 2004 the Government's SEN policy *Removing Barriers to Achievement* set out a programme of action on early intervention, removing barriers to learning, raising

expectations and achievement and bringing improvements through partnerships between agencies. A £1.1 million programme delivered by the Training and Development Agency is helping to increase SEN skills in mainstream schools to increase the numbers of children participating in mainstream education.

- 3.4 Other government policies such as *Every Child Matters* and the *National Service Framework for Children, Young People and Maternity Services*, have set objectives for children's health and social care - including a standard for disabled children and young people. A key aim of these policies is better inter-agency working. The *Early Support* programme focuses on this and recommends families are assigned 'key workers' to help them negotiate access to services.
- 3.5 Government has recently announced the £340 million *Aiming High for Disabled Children* programme, for 2008-11. It has three priority areas – access and empowerment, responsive services and timely support and improving quality and capacity. The funding includes £280m for increasing short-breaks/respite care for disabled children, £35m for a childcare accessibility project to improve access to childcare for disabled children and £5m for developing parents' forums in every local authority area.



## **Part Two**

### **The Big Priorities**

#### 4. Priorities for *Valuing People Now*

- 4.1 *Valuing People* still has strong support from people across England and from government. There is no suggestion that we change the basic policy. **Unless explicitly stated in *Valuing People Now*, all policy statements in the original *Valuing People* will continue to apply in the future.** This document aims to:
- make changes or additions to the policy where that is needed;
  - be clear about priorities for the next three years;
  - describe how government expects progress to be made over that period.
- 4.2 The actions for local health and social care partners in this report are options for consideration as good practice and not mandatory unless stated below or in previously issued guidance/policy. The impact of the policy has been assessed in the partial impact assessment as part of the consultation. Two new requirements proposed as part of this policy would be:
- funding and commissioning responsibility for specialist learning disability services (social care services) being transferred to local authorities (see section 16);
  - action for commissioners, when independent sector health placements come under review, to follow existing guidelines and avoid commissioning inappropriate types of residential health placements (see section 16).
- 4.3 *Valuing People* is a whole life policy for equal citizenship. This means thinking about all public services and all parts of people's lives. However, it is important that we focus on the issues that will have most impact. Therefore, *Valuing People Now* identifies five major priorities for everyone, including government itself, for the next three years.
- 4.4 These priorities for 2008-2011 are:
- **The Personalisation Agenda.** People having real choice and control over their lives and services through individual budgets, direct payments and person centred planning, underpinned by strong self-advocacy and family carer support;
  - **What people do during the day** (and evenings and weekends). Helping people to be socially included in their local communities - with a particular focus on paid work - and as a result seeing big changes in traditional day services;
  - **Better health.** Ensuring that the mainstream NHS provides full and equal access to good quality healthcare and that specialist healthcare services are modernised;
  - **Access to housing** that people want and need, with a particular emphasis on proper housing, i.e. home ownership and real tenancies;
  - **Making sure that change happens** and the policy is delivered. In particular, making learning disability partnership boards more effective and checking that the things we say should happen, do actually happen.
- 4.5 In taking forward these priorities, there should be a particular focus on achieving positive outcomes for people who are at the greatest risk of exclusion, i.e. people with complex support needs and people from minority ethnic communities.

## 5. Personalisation

### The Big Headlines

- “Direct payments, individual budgets and the In Control programme are not fleeting experiments but central to the direction of travel for social care for the next decade and beyond” Ivan Lewis, Minister for Care Services
  - A renewed focus on supporting person centred planning

#### 5.1 Where Are We Now

- 5.1.1 *Valuing People* said that people should have much more choice and control over their lives, services and supports. Planning and commissioning decision should be based on what people have said they want and need in their lives through their own person centred plans. People should increasingly get direct control of services, either through a direct payment to purchase their own services and supports or control over the kind of support they receive. Take up of direct payments has increased significantly, but is still only 1.1% of total learning disability budgets (source PSSRU).

Year	Number of people with a learning disability in receipt of a direct payment
2000/2001	250
2001/2002	480
2002/2003	880
2003/2004	1840
2004/2005	3385
2005/2006	5485

The *Valuing People* programme prompted and supported the In Control project. This tried out new ways of giving people control over their services. The initial In Control evaluation showed how people (and their families) were much more satisfied with their lives and services and were getting better outcomes within available resources.<sup>2</sup>

- 5.1.3 Other Government policies including *Improving the Life Chances of Disabled People* and *Our Health, Our Care, Our Say* built on these ideas to modernise social care and develop individual budgets to give people more choice and control. Individual budgets are being piloted by 13 local authorities and cover adult social care funding, Supporting People, the disabled facilities grant, Access To Work, integrated community equipment services and the independent living fund. Once it is known how best to make individual budgets work, government will consider their wider roll out for the rest of England. In addition, two thirds of local authorities have joined the In Control programme. For direct payments, a national programme is in place to help increase take-up.
- 5.1.4 Person centred planning has been shown to work. The world’s largest study into person centred planning<sup>3</sup> described how it helps people get improvements in important parts of their lives and indicated that this was at no additional cost. The *Valuing People* Support

<sup>2</sup> A report on in Control’s first phase 2003-2005, *In Control*, 2006

<sup>3</sup> The Impact of Person Centred Planning. Robertson et al, April 2005

Team have worked with CSCI in developing and started to pilot tools so that their inspectors can make checking on person centred planning an important part of their work. The Department of Health and the Department for Children, Schools and Families are funding the introduction of person centred approaches for young people at the time of transition to adult services. (see section 13).

- 5.1.5 Despite all this, too few people have access to proper person centred planning, receive a direct payment or are involved with an individual budget. In too many local authorities, person centred planning is not at the centre of how things are done. The challenge for the next three years is to take all this innovative work and make sure that more – and eventually all – people have real choice and control over their lives and services.

## 5.2 Next Steps

### *Person Centred Approaches*

- 5.2.1 Effective person centred planning is an essential starting point for personalisation and the person centred planning objectives in *Valuing People* need to be delivered for everyone. To support local people to do this, the *Valuing People* delivery programme will include:

- regional and local support networks;
- updated good practice guidance in line with the research findings;
- further work with providers to help them become more person centred;
- expansion of the person centred transition initiative (see section 13)

### *Person Centred Support*

- 5.2.2 Giving people more choice and control over the support they receive will mean that many things will need to change. For example:
- local authorities and others will need new systems that give people more control over their support and allow them to use resources more flexibly;
  - commissioners will need to change how they work and what they decide to buy, including getting better at listening to people;
  - more individuals and families will be commissioning their own services;
  - providers will need to work differently, in particular by setting up new types of services around individuals rather than groups;
  - staff and professionals working in services will need to work in different ways and be trained and often employed differently;
  - people who inspect and check services will need new ways of making sure services are personalised and meet the outcomes that people need and want;
  - more consideration being given to responding to people's cultural and religious beliefs;
  - there will be an increased focus on the use of assistive technology to support people in their daily lives.
- 5.2.3 This is all a major challenge to public services. The Department of Health is working with key stakeholders (including ADASS, LGA and the Improvement and Development Agency (IDeA)) to develop a programme to drive and support the necessary changes. The individual budget pilot programme will continue until December 2007 with evaluation completed in April 2008 (details can be found at:

www.individualbudgets.csip.org.uk). Learning from the pilot sites will be used to develop national good practice advice on different aspects of the personalisation agenda later this year. The independent In Control' project will continue working with authorities beyond the individual budget pilots.

- 5.2.4 The work to increase direct payments uptake will continue with national support available through the Department of Health and its regional presence. Local authorities and partners should by now have their own plans to increase take-up.
- 5.2.5 We know that an obstacle to direct payments for people with learning disabilities has been the lack of the right support to take on the responsibility of a direct payment. This is often best done through local user led organisations (see section 9). As user led organisations develop, we expect they will have the expertise to be inclusive of people with learning disabilities and support them to make maximum usage of individual budgets and direct payments.

### 5.3 Action Summary

#### 5.3.1 Nationally:

- the Government will be working with other stakeholders to take this agenda forward
- increasing take-up of person centred planning will be a priority for the *Valuing People* delivery programme
- personalisation, including person centred planning, will be a key focus for the next three years for social care, supported by the LDDF

#### 5.3.2 Locally

- people with learning disabilities should be central to direct payment take-up strategies
- local partners should review and develop local person centred planning strategies and prioritising support for person centred planning as outlined in other sections of *Valuing People Now*

## 5.4 The Vision for Three Years From Now

This will be different.....	We will know this because .....
People will have much more choice and control in the services and supports that they use and the lives that they lead	Discussions will be held with the regulator about how the inspection and review process will tell us this
Many more people will be using individual budgets and direct payments	Nationally collected and analysed data will tell us this
The majority of people have access to person centred planning and person centred approaches will have become the norm in services	Partnership boards report on progress as part of their wider public reports on <i>Valuing People</i>
Many more schools across the country will be using person centred approaches in helping people to get ready for life after school	Data from the person centred transitions programme will tell us this

## 6. **What People Do During The Day (and evenings and weekends)**

### **The Big Headlines**

- Stop thinking about ‘day services modernisation’ and instead work on people getting better lives in their communities by using person centred planning, with access to work as the main starting point
- A cross government programme to bring together funding and decision making around jobs, education and adult day services: the Getting a Life project
- A five year strategy to improve post 16 education for people with learning disabilities: ‘Progression through Partnership’
  - The Department for Work and Pensions to work with other government departments and key stakeholders including employers and providers to increase access to real, paid jobs for people with a learning disability
- The Department for Work and Pensions to reform its employment provision to be more flexible to individual needs and support independent living

### 6.1 Where Are We Now?

- 6.1.1 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 activities. Yet for many people this does not happen and they still spend too much time in traditional day services.
- 6.1.2 Employment levels for people with learning disabilities have increased slightly over the last decade but remain disappointingly low. Different surveys give figures of between 5% and 17% of people being in work. In contrast, employment levels are 47% for disabled people (up from 38% a decade ago) and 74% for the working age population as a whole.

- 6.1.3 Access to post-16 education continues to be a problem because of priority being given to young people and achieving level two qualifications. The Learning and Skills Council's strategy for learners with learning difficulties and/or disabilities '*Learning for Living and Work*' (2006) undertook to stop commissioning poor quality provision by September 2008. (For example, where people repeat the same course year after year or there is no focus on getting into work). Some courses have already ceased. Although alternatives were developed in most cases, in some areas people returned to traditional day services – which is not desirable.
- 6.1.4 *Valuing People* proposed 'day services modernisation' in relation to services provided by adult social services departments. We now think that this term is unhelpful. It encourages people to think about buildings rather than outcomes. Some authorities have used this policy to justify cuts in services. For others, small day centres have replaced big ones, but what people do with their time has hardly changed.
- 6.1.5 Changing this picture means that people and organisations responsible for adult social services, employment, education, leisure and community development will need to work better together in the future.

## 6.2 The Next Steps

### *Adult Social Care Day Services*

- 6.2.1 The concept of day services modernisation is unhelpful if people understand it as making day centres smaller. The policy objective is to support people to live the lives that they want as equal citizens in their community - in other words social inclusion. One outcome will be major changes to many existing day services.
- 6.2.2 The two starting points to achieving this are:
- effective person centered planning. The outcomes from this will inform planners what services and supports should be put in place instead of traditional day services. As more people take up direct payments and individual budgets, they will be taking these decisions for themselves and the speed of change will increase;
  - forward planning. Good person centre planning can take time. Rather than use this as an excuse for inaction, effective managers will already be planning to develop what we know people say is most important to them and what society expects for all other people – access to real, paid work. As well as providing income, paid work opens up other opportunities such as social networks. It is an achievable objective for almost everyone, including people with complex disabilities.
- 6.2.3 We expect the end result of this will be significant changes to many existing day centres. However, this should not be the starting point. The starting point is effective person centred planning that finds out what people want in order to plan new services that will achieve social inclusion.
- 6.2.4 Experience shows us that the best way for local authorities to develop services that achieve social inclusion is to:

- work in partnership with the employment, education and leisure sectors, using resources flexibly between sectors and linking into local strategic partnerships and local area agreements;
- prioritise making support for person centred planning available to people in receipt of traditional day services – and direct payments and individual budgets;
- make sure young people with learning disabilities (including those at special schools) get equal access to the entitlement to work experience for children and young people in schools and colleges. Work with independent supported employment agencies to help this happen;
- prioritise change for people with high support needs and people from black and minority ethnic communities who currently use traditional day centres;
- think beyond nine to five working days and include evenings and weekends – but also recognise that for people living with their families, existing day centre hours provide important breaks for both the family and the person themselves;
- have an objective that no young person leaving school and college in the future goes into a segregated day service or centre;
- invest in specialist employment support agencies but see Jobcentreplus as the main resource to help people to find jobs;
- develop partnerships with major employers to help find paid employment – with public services leading by example;
- recognise the importance of planning for people who are past the retirement age and may want things other than work;
- establish a local outcome (e.g. within three years) that no day centre should be segregated. Only invest in integrated facilities and have a de-commissioning strategy for traditional services.

### *The Getting A Life Project*

- 6.2.5 A major barrier to people having real choice and control over their lives is the way that different services plan and fund support. To help address this, the Office of Disability Issues, Department of Health, Department of Work and Pensions, Department for Children Schools and Families and Department for Innovation Universities and Skills have established the Getting a Life demonstration project.
- 6.2.6 A small number of localities will join the project and explore how to bring together the funding and planning processes around:
- special educational needs transition planning;
  - post-16 education planning and provision;
  - disability employment advice and support;
  - local authority social care assessment and support.
- 6.2.7 Starting from person centred planning, the aim is to achieve an integrated assessment and decision-making process that will allow people to use public resources flexibly in a way to get the outcomes they want. The initial focus of the work will be on young people going through the transition to adult life. The project has already started. Learning from the project will be shared quickly so that other parts of the country can take on new ideas at an early date.



## *Employment*

- 6.2.8 A cross-government working group led by the Department of Work and Pensions is developing an action plan to increase the number of people with learning disabilities in paid work in response to the report *Improving Work Opportunities for People with a Learning Disability*. This is focusing on:
- improving partnership between different sectors;
  - increasing the focus on work at the time of transition;
  - making current work programmes work better for people with a learning disability;
  - making sure the benefits system helps people into work;
  - supporting and encouraging employers to employ people with learning disabilities.
- 6.2.9 Early actions from this include:
- a pilot project in Newham, with a national dissemination programme, to test out new ways of inter-agency working to increase employment levels;
  - advice and guidance to the employment sector on achieving the inclusion of people with learning disabilities in mainstream employment initiatives;
  - reviewing existing benefits guidance to improve its clarity about processes and rules;
  - action to ensure that the skills of small providers of employment support for people with learning disabilities are fully used when tendering for the delivery of work programmes;
  - producing and sharing best practice advice in the employment of people with a learning disability.
- 6.2.10 The Department for Work and Pensions is reviewing its employment services for disabled people and will consult on proposals shortly. This is in recognition of the need to do more to help people with higher support needs into employment and deliver the vision set out in *Improving the Life Chances of Disabled People*, that:
- “Future government policy should be designed to ensure that in twenty years time any disabled person who wants a job and needs support to get and keep a job anywhere in the country should, wherever possible, be able to do so. Any employer wanting to employ a person should be able to find the right person and the right support.”
- 6.2.11 The review is examining ways to make services more flexible to the needs of individual disabled people, and thus help them get and maintain paid employment, including:
- a greater focus on those who need specialist support, such as many of those with a learning disability;
  - less prescription and greater flexibility;
  - better links between elements of provision;
  - better consistency and quality of provision;
  - improved effectiveness in helping disabled people into work
  - improved help to enable people to maintain their job independently;
  - an improved service for people receiving long-term support.

- 6.2.12 The public sector itself is a huge employer. Government and its associated bodies will therefore demonstrate a lead and ensure that its employment practices lead to increased numbers of people with learning disabilities in paid work across the public sector.

#### *Post 16 Education*

- 6.2.13 The then Department for Education and Skills, Department of Health, and Department for Work and Pensions published a strategy in June 2007 called *Progression Through Partnership*. It 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 provide positive outcomes;
  - improving the clarity and flexibility of funding to support learning and placing the individual at the centre of planning services.

A detailed delivery plan is due to be published.

- 6.2.15 From autumn 2008, the Foundation Learning Tier will give new ways for learners from the age of 14 to progress at a pace suited to their needs and talents. With an emphasis on employability skills, the framework will provide preparation for independent living.

#### *Community Capacity Building*

- 6.2.16 Local communities need to be ready and willing to welcome people as citizens. Local authorities will therefore need a strategy, linked to Local Area Agreements, for community capacity building that addresses how all people and organisations can develop the attitudes and skills to involve learning disabled people. It will also need to consider physical resources – for example having public toilets in town centres with adult changing facilities so adults with personal care needs can use their town centre.

### 6.3 Action Summary

#### 6.3.1 Nationally:

- the cross-government Getting a Life project,
- a five year delivery strategy around post 16 education (*Progression Through Partnership*);
- cross-government action, led by the Department for Work and Pensions, to achieve an increase in the number of people moving into real, paid jobs;
- consultation on the redesign of the Department for Work and Pensions employment services for disabled people that will actively seek and respond to the views of people with learning disabilities;
- the Department for Work and Pensions and Department of Health funded pilot in Newham to learn how best to instigate local action towards increased employment, with the learning shared nationally;
- prioritisation of this issue within the *Valuing People* delivery programme for the next three years and for the LDDF in delivering the social exclusion employment indicator;
- government departments will review their own employment of people with a learning disability as part of Disability Equality Strategies.

### 6.3.2 Locally:

- support for person centred planning for people attending traditional day centres should be a priority;
- person centred transition processes should be in place to support young people into jobs and education rather than traditional day centres;
- strong partnerships should be developed between adult social care, employment, education and leisure sectors to develop strategies in response to outcomes from person centred planning;
- local re-investment strategies should move from traditional day services to a social inclusion strategy;
- local public sector organisations to review and increase their employment levels of people with a learning disability.

### 6.4 The Vision For Three Years From Now

This will be different.....	We will know this because .....
More people will be in paid, real jobs	A new public services agreement indicator will collect this information.
Government itself will be employing more people with a learning disability in paid jobs	Government employment data will demonstrate this
More people will be doing the post 16 education courses that they want and these will help people towards getting real jobs	Data collected by the Learning and Skills Council will tell us this is happening
People will be spending more time doing things they choose during the day, rather than receiving traditional day services, and using individual budgets and direct payments to do this	Nationally collected and analysed data will tell us whether this is happening
The Getting a Life project will have shown how to bring together different funding and decision-making processes around what people do during the day.	The demonstration sites will have extended to many other parts of the country

## The Big Headlines

- A new primary care service framework to support PCTs in commissioning comprehensive health checks and better primary care access for people with learning disabilities
- Good practice guidance issued on specialist learning disability health services
  - A national awareness and education programme for the NHS about the Disability Equality Duty
- SHAs, PCTs and providers to action improvements in bed based services arising from the Healthcare Commission's learning disability audit

### 7.1 Where Are We Now

- 7.1.1 Most people with learning disabilities have poorer health than the rest of the population and are more likely to die at a younger age. Despite this, there is clear evidence that their access to the NHS is often poor and characterised by problems that undermine personalisation, dignity and safety. At its worst, reports have suggested that this leads to abuse, undiagnosed illness and in some cases avoidable death.<sup>4</sup>
- 7.1.2 Since these reports, the Parliamentary and Health Services Ombudsman has established an inquiry into complaints made by families of those who died as identified in *Death by Indifference*. The Secretary of State for Health has established an independent inquiry into access to healthcare for people with learning disabilities to understand the wider NHS issues. Work is underway to implement recommendations made from the Disability Rights Commission formal investigation.
- 7.1.3 There have been a number of other national and local actions on health, for example:
- the Department of Health, working with NHS Primary Care Contracting, has developed and published a framework to support Primary Care Trusts to commission primary care services for people with learning disabilities<sup>5</sup>. This will support the NHS in delivering the commitment in *Our Health, Our Care, Our Say* to introduce regular comprehensive health checks for people with learning disabilities. Evidence shows that such checks identify previously unknown health conditions and result in treatments that improve people's health;
  - 'Questions to Ask'<sup>6</sup> is a short leaflet of tips and advice about getting the best out of medical appointments. The easy to read version of the leaflet was developed

<sup>4</sup> 'Equal Treatment: Closing the Gap,' 2006, Disability Rights Commission:  
<http://www.equalityhumanrights.com/en/publicationsandresources/Disability/Pages/Formalinvestigations.aspx>

'Treat Me Right: Better health for people with a learning disability,' 2004, Mencap:  
[http://www.mencap.org.uk/download/treat\\_right.pdf](http://www.mencap.org.uk/download/treat_right.pdf)

'Death By Indifference,' 2007, Mencap  
<http://www.mencap.org.uk/html/campaigns/deathbyindifference/reports.asp>

<sup>5</sup> 'Management of Health for People with Learning Disabilities in Primary Care – July 2007', NHS Primary Care Contracting

<sup>6</sup> <http://www.ldhealthnetwork.org.uk/questioninfo.pdf>

and tested with a range of groups including those with learning disabilities. These leaflets will be distributed to most GP surgeries and pharmacies and be available on request;

- in some places strategic health facilitators have helped to build capacity and share knowledge in the wider NHS about how to support people with learning disabilities and their families. However, only a minority of PCTs have so far invested in this way.

7.1.4 The focus on closing long stay hospitals and NHS campuses (see section 8), along with the important agenda of meeting people's general health needs, has meant that in some parts of the country there has been inadequate attention paid to specialist learning disability health services (including secure provision). The Healthcare Commission reports into abuse in both Cornwall and Sutton and Merton identified this as a significant problem.

7.1.5 There is thus a major agenda for the NHS – to achieve policy commitments about health inequalities and the inclusion of people with learning disabilities in the mainstream NHS, whilst also ensuring good quality, evidence based specialist learning disability health services in all parts of the country.

## 7.2 The Next Steps

7.2.1 The underpinning problem with health and healthcare for people with learning disabilities is that of the low priority and focus given to this area by NHS organisations. The Chief Executive of the NHS has written to all SHAs and PCTs stressing they must have sufficient commissioning capacity and expertise in learning disabilities. The NHS also needs to work better with other partners, in particular the local learning disability partnership (see section 15), so that specialist and mainstream health services are commissioned and delivered as part of the multi-agency *Valuing People* agenda.

7.2.2 Underpinning this will be work to help ensure the NHS fully respects the position of people with learning disabilities as equal citizens, through action such as:

- the design and delivery of a national awareness and education programme for the NHS about the Disability Equality Duty, and specific advice on compliance in relation to people with learning disabilities;
- the Department of Health Human Rights in Healthcare project, supporting NHS Trusts to use a human rights based approach to improve service planning and delivery for individuals with learning disabilities;
- improved communication between the NHS and all its users, particularly those with learning disabilities;
- a disability equality impact assessment of recent measures to increase patient choice.

### *Primary Healthcare*

7.2.3 In response to the DRC report, the Department of Health established a task group, with the DRC, to take this work forward. The following actions are resulting from this:

- a framework for commissioning primary care for people with learning disabilities (see 7.1.3). This provides practical help not only in commissioning annual health checks, but in achieving wider objectives for improving primary

care services, including providing better coordinated access to primary, community and specialist service, providing individualised health action plans, and promoting better health outcomes and better involvement in health care for people with learning disabilities;

- the development of GPs with a special interest in learning disability who will be a resource to other GP practices in their area in improving the quality of services to people with learning disabilities;
- the Department has developed a preferred framework for health checks, which the *Valuing People* Support Team is promoting at regional events;
- the National Clinical Director for Primary Care is leading a national programme of work to improve access to and quality of primary care, which will specifically include issues that affect access for people with learning disabilities;
- when establishing new Local Involvement Networks (LINKs), subject to completion of the legislative process, the Department of Health will make sure that all groups and communities are involved in LINKs and gain a stronger voice in shaping local services.

7.2.4 The policy promise to introduce comprehensive health checks for people with learning disabilities is still to be delivered. This remains a departmental priority in terms of contractual negotiations with GPs. However, introducing health checks does not have to wait for national agreement and PCTs are likely to develop more comprehensive service frameworks (covering not just health checks) by using the NHS Primary Care Contracting framework to commission these services locally. The Department will be encouraging this approach and promoting best practice by PCTs.

7.2.5 The 2001 *Valuing People* targets and objectives in relation to health action planning were not achieved. Updated good practice guidance on health action planning to help increase the number of people with primary care-led health action plans will be produced in the near future.

7.2.6 Lord Darzi's recently published interim report on the NHS Next Stage review described how further work will be done on the future strategy for primary care and community services. This includes the changes needed in terms of service models, training, accountability and other issues. This work will address equality issues.

7.2.7 The Department of Health, working with the NHS, will shortly be setting out a vision of how PCTs will become world class commissioners. Two key parts of this will help deliver the response to the DRC investigation. PCT action on improving the health of their local population will particularly focus on eliminating avoidable deaths and dramatically reducing health inequalities. PCTs will look at the long term health needs of the whole population and commission services that will meet them. They will do this by actively engaging and listening to local people. The Department of Health will ensure that PCTs include people with a learning disability in this debate. Finally, the Department of Health will ensure that PCTs are aware of options for consideration as best practice relating to people with learning disabilities.

#### *Hospital and Acute Healthcare*

7.2.8 *Valuing People Now* will not pre-empt the conclusions of the independent inquiry into healthcare of people with learning disabilities. Government will seriously consider the

inquiry's recommendations and act accordingly. In the meantime, all PCTs and general hospital trusts should be ensuring that:

- Disability Equality Schemes, which they are legally required to have, address their abilities and resources to provide general healthcare to people with learning disabilities;
- there are sufficient staff available with skills and training in working with people with learning disabilities, for example through investing in liaison nurses between mainstream and specialist learning disability services;
- links exist with specialist learning disability services to call in additional help, training and advice when needed;
- policies and procedures are in place to support admissions and treatment and reduce identified risks. Attention should be paid to people with complex needs on admission to hospital, making sure there is no inappropriate reliance on family carers.

### *Specialist Learning Disability Health Services*

- 7.2.9 Every PCT should be commissioning (in partnership with its local authority colleagues) a comprehensive specialist learning disability service based on evidence and best practice. Links should be made with regional and national strategies for forensic services. Good practice advice to assist this has been published<sup>7</sup>. Good practice advice on the role of learning disability nursing will be issued shortly by the Chief Nursing Officer.
- 7.2.10 Following the Healthcare Commission's reports into abuse in Cornwall and Merton and Sutton, the Commission undertook an audit of bed-based learning disability services in the NHS and private healthcare sector. This report has just been issued and it describes poor quality services and inadequate service commissioning. Providers will be expected to implement recovery plans to address any problems identified by the audit and SHAs will performance manage those plans in conjunction with PCTs who commission the services. Particular attention should be given to women in secure settings, where there is anecdotal evidence of women being more at risk.
- 7.2.11 The forthcoming NHS operating framework will cover all the Public Service Agreements (PSAs), including those led by other government departments. This will include the Cabinet Office PSA on socially excluded adults which has two indicators focusing on learning disability (living independently and getting and staying in employment). The PSA targets which form part of the wider government commitment to tackling social exclusion, reflect the government's commitment to this agenda and to help drive delivery. The Operating Framework will include a strong message on how PCTs should act upon *Valuing People* Now by working closely with LAs, through the LAA process, to identify local priorities. We would expect PCTs to pursue service improvements on learning disability through this route, with a particular focus on making progress on campus closure.
- 7.2.12 The operating framework will alert PCTs to prepare for the transfer of learning disability funding to LAs (see section 16.2), subject to the outcome of the consultation. It will also require SHAs, PCTs and Trusts to deliver action plans setting out what they

---

<sup>7</sup> 'Commissioning specialist adult learning disability health services', Department of Health, 2007

are doing to address the shortcomings in learning disability services identified through the Healthcare Commission's audit. Trusts performance on learning disability services will form part of the Healthcare Commission's annual assessment.

- 7.2.13 The new joint regulator, the Care Quality Commission, is due to be established in October 2008 and will take on responsibility for the regulation of health and social care from April 2009. The work to determine the detail of regulation and registration under the new commission will include specialist learning disability services.

### *Mental Health*

- 7.2.14 In terms of people's mental health, the *National Service Framework for Mental Health* should benefit people with learning disabilities as much as anyone else. While there are some excellent examples of positive practice, too many people with learning disabilities still find it difficult to access mainstream mental health services. Since 2004, the 'Green Light Toolkit' has helped mental health services judge progress and plan action. A national programme of support is available to help with this. Discussions are beginning about mental health policy beyond 2009 (the end of the NSF period). That policy will learn the lessons of the failure to fully extend the benefits of the NSF to people with learning disabilities and will better integrate mental health care for people with learning disabilities into mainstream service development.

## 7.3 Action Summary

### 7.3.1 Nationally:

- the recommendations from the Independent Inquiry into Healthcare will be received by the Secretary of State, considered and responded to;
- the working group responding to the DRC report will continue its work until nationally led responses to the DRC recommendations are properly in place;
- achieving comprehensive health checks for all people with learning disabilities will continue to be an important government objective;
- there will be renewed good practice guidance on and delivery support on primary care engagement in health action planning and health facilitation;
- good practice guidance on commissioning specialist learning disability health services has been published and guidance on the role of learning disability nurses will be published shortly;
- future developments in mental health policy and delivery will fully include the mental health needs of people with a learning disability;
- strategic health authorities and the *Valuing People* delivery programme will work together to progress and review progress on the health agenda;
- the health agenda will be a priority for the *Valuing People* delivery support programme for the next three years and for the LDDF in delivering the PSA indicator on health equalities;
- the operating framework will specifically address learning disability.

### 7.3.2 Locally:

- SHAs and PCTs should ensure they develop sufficient commissioning expertise and capacity in relation to the health and healthcare needs of people with learning disabilities and engage in multi-agency planning through their partnership board;



- PCT and NHS trust disability equality schemes should include specific action in response to the health inequalities facing people with learning disabilities;
- PCTs should ensure that their commissioning strategies address the needs of people with learning disabilities and use the framework developed by NHS Primary Care Contracting to help commission services that better reflect these needs, including comprehensive health checks;
- PCTs should use the good practice guidance on specialist health services to review services, as requested by the Healthcare Commission, and progress action plans arising from the Healthcare Commission audit;
- local action plans should use the 'Green Light Toolkit' to improve mental health services for people with a learning disability;
- general hospitals should review their capacity to provide quality services to people with learning disabilities in advance of the findings and recommendations of the independent inquiry into access to healthcare.

#### 7.4 The Vision For Three Years From Now

This will be different.....	We will know this because .....
PCTs will be using information about the health of people with learning disabilities, and their engagement with people with learning disabilities, to commission inclusive mainstream and specialist health services	Local information on health service delivery will demonstrate equality of access in line with DED requirements. There will be reduced usage of out of area placements
The majority of people will have an identified health facilitator, health action plans and regular comprehensive health checks	PCT commissioning plans, developed in partnership with local service users, will identify how local needs are being addressed and inform local learning disability partnership reviews of progress
PCTs will be actively engaged as full partners in the local multi-agency planning and review of learning disability services	Local learning disability partnerships will report full and active participation from primary care trusts with up to date action for health frameworks

## 8 **Improving People's Housing Situation**

### **The Big Headlines**

- A joint CLG/DH programme to promote the inclusion of people with learning disabilities in mainstream housing initiatives
  - An increased focus on access to home ownership and assured tenancies
    - Funding to support the closure of NHS campuses

#### 8.1 Where Are We Now?

- 8.1.1 Most people with a learning disability still do not have their own home. Over half of adults continue to live with their families, many into middle age and even older. Some

people and their families want this to be the case – many more do not. Many others live in residential care, adult placements or other forms of shared housing that they have not chosen. Only 15% of adults with a learning disability have a secure, long term tenancy or own their own home – compared to over 70% of the general adult population who own their own home and nearly 30% who rent.

- 8.1.2 Where people do have their own tenancies with support provided by a third party, their rights as tenants are often overlooked on a day to day basis because of their need for that support. Further formal research on this issue to identify problems and solutions would help.
- 8.1.3 Some inappropriate forms of living arrangements are coming to an end – in particular people living long term as an NHS in-patient. The 2001 *Valuing People* target to close all long stay hospitals by 2004 was not achieved – but only one hospital remains open. Local managers have committed to close Orchard Hill in Sutton by 2009 at the latest.
- 8.1.4 *Our Health, Our Care, Our Say* made a commitment that people living in NHS campuses would move out to ordinary housing and support, and the campuses would consequently close. This affects up to 3,000 people. Progress on this will be checked through national data collection.
- 8.1.5 There are a number of innovative mainstream housing policies. For example, Supporting People has helped many people with learning disabilities to live in their own home - in 2005/06, £ 388.8m of Supporting People funding was spent on services for people with learning disabilities. Beyond this, however, there is limited evidence that mainstream housing policies are having a positive impact upon people with learning disabilities. Changing this and shifting the culture of care management to promote greater choice and control over people's housing situation are the two key housing challenges for *Valuing People Now*.

## 8.2 The Next Steps

- 8.2.1 *Valuing People* rightly emphasised that people should have a choice of housing and did not prescribe one model for everyone. However, paragraph 8.1.1 shows how the housing situation of people with learning disabilities differs from what the rest of the society expects for themselves. Learning disabled people themselves tell us they want more housing rights. Therefore, within the overall policy of a range of housing options being available, **local authorities should concentrate on promoting access to and increasing the numbers of people who live in their own homes or have assured tenancies in rented accommodation.** A new public service agreement indicator about the accommodation status of people with learning disabilities will track progress on this.
- 8.2.2 To help ensure that mainstream housing policies are inclusive of people with learning disabilities, Communities and Local Government and the Department of Health through the *Valuing People* delivery programme, will agree, resource, and work together on a programme of work that will cover the content of paragraphs 8.2.3 to 8.2.6 below.
- 8.2.3 Improving information about housing and its delivery so that people can make informed choices from a range of quality housing options. This will include:

- the Housing Corporation and *Valuing People* delivery programme jointly auditing existing housing information with respect to people with learning disabilities;
- working with a group of leading housing associations to develop best practice guidance on housing for vulnerable tenants;
- producing best practice advice on promoting the tenancy rights of people with learning disabilities.

- 8.2.4 Improving information about housing need so that the needs of people with learning disabilities are built into housing planning. This will include:
- building on best practice with housing registers and strategic needs assessment such as the London accessible housing register and assessment framework;
  - developing advice to local authorities on identifying the housing needs of people with learning disabilities.
- 8.2.5 The Government's 'Mixed Communities' initiative aims to help create communities where people from all backgrounds, income groups and disabilities choose to live.<sup>9</sup> For people with learning disabilities in mixed communities, this will include inclusion in mainstream services, choice about where and how they live and promoting independence with support. When drawing up Mixed Community demonstration plans, CLG want local authorities to consider how to expand the range and choice of housing, and support services for people with learning disabilities.
- 8.2.6 Increasing housing options and the range and quantity of housing that is available to people. This will include:
- exploring a local demonstration project to increase housing options for people with learning disabilities;
  - action to ensure that people with learning disabilities benefit from government home ownership initiatives, including Home Ownership for people with Long Term Disabilities (HOLD) and the New Build Home Buy scheme (i.e Shared Ownership);
  - Housing Corporation funded investment in social housing. The Housing Corporation's prospectus encourages bids for housing for vulnerable people including people with learning disabilities.
- 8.2.7 For social services commissioned housing and support, individual budgets will help people have greater control over their housing situation. In the initial In Control pilot most people using residential care chose to move into their own homes. Since 1990<sup>10</sup> policy has been that local authorities should explore supporting people in their own owned or rented home as the first option and only if this is not possible, or the person explicitly does not want it, turn to other options such as residential care. People assessed and funded as needing NHS continuing care can and should still be supported to live in their own homes, with additional intensive healthcare input where needed.
- 8.2.8 The programme to support the closure of NHS campuses will continue. The Department of Health recently announced a £175m capital fund to help develop replacement housing and will work with the Housing Corporation to promote bidding for joint

<sup>9</sup> <http://www.rmd.communities.gov.uk/project.asp?intProjectID=12271>

<sup>10</sup> 'Community Care in the Next Decade and Beyond,' 1990, Department of Health

capital funding of housing schemes. In addition, the local government financial settlement, details of which will be announced shortly, will allocate resources as a grant to support the extra revenue costs involved in supporting people in ordinary housing rather than NHS campus provision

- 8.2.9 Improving housing for people with learning disabilities is an issue for housing authorities, in partnership with social services authorities. This should be taken forward through the local learning disability partnership board. To help this, housing will be made a priority for local use of the LDDF for the next three years.
- 8.2.10 Recent decisions by Social Security Commissioner Turnbull have caused concerns for some people with learning disabilities who live in rented accommodation about the amount of rent that can be met through housing benefit. Government understands these and wider concerns and is working together to address the causes. This action will be built on the principles of:
- recognising that for some people, housing design and management linked to their disability might increase costs above the local norm;
  - designing 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.

### *Support*

- 8.2.11 Having the right support is essential for many people to live successfully in the housing of their choice. With the introduction of Individual Budgets and Direct Payments, people will increasingly decide themselves about their support. For others, high quality individualised support from existing providers will continue to be required. The content of all the other sections of *Valuing People Now* is central to support providers, in other words support providers need to:
- use person centred approaches and support person centred planning (section 5);
  - change practice in line with the wider personalisation agenda (section 5);
  - focus on supporting people into paid work as a priority (section 6);
  - support people to achieve social inclusion in their communities (section 6);
  - ensure people are healthy through staff awareness of health and links with the local NHS (section 7);
  - work in ways that give people rights and control (section 9);
  - have a workforce and training strategy that recruits and retains high quality staff (section 14);
  - provide services and support that responds to people's different cultural backgrounds (section 11).
- 8.2.12 The Supporting People strategy, published in June 2007 described how the programme aims to improve housing related support services through a greater focus on service users and their needs, a better relationship with the third sector, and by increasing efficiency and reducing bureaucracy. People with learning disabilities continue to be an important 'target group' to benefit from Supporting People. The recently launched Supporting People outcomes set ensures that people with learning disabilities are empowered to have their own say on outcomes achieved against their personal support plan. This will provide evidence that their quality of life is improving.

### 8.3 Action Summary

#### 8.3.1 Nationally:

- a joint CLG/DH housing programme as outlined above;
- housing to be a priority for the LDDF in line with the PSA objective on settled accommodation and for the *Valuing People* delivery programme for the next three years;
- £175m capital funding and a grant to local authorities to support revenue costs, to enable the closure of the NHS campuses.

#### 8.3.2 Locally:

- an increase in people receiving individual budgets and direct payments in order to increase their choice and control over their housing situation;
- local authority care managers should have an increased focus on home ownership and assured tenancies as a model for housing and support;
- through person centred planning, local authority care managers to understand for adults still living with families, whether that is the person's preferred option and instigate plans accordingly;
- all NHS campuses to be closed through people moving to ordinary housing and support by 2010 in line with *Our Health, Our Care, Our Say*;
- partnership boards should monitor the progress and process of local campus closure, or for local individuals in campuses elsewhere;
- support providers should be familiar with, and progress action across, all issues identified in *Valuing People Now*.

### 8.4 The Vision For Three Years From Now

This will be different.....	We will know this because .....
More people with learning disabilities will own their own home or living in rented accommodation with assured tenancies	The new PSA accommodation indicator will tell us this is happening
Housing authorities will be including people with learning disabilities in their housing plans, based on accurate information of what people want and need	The Supporting People outcomes set and local government performance framework data will tell us this is happening
People's rights as tenants are being properly respected by landlords	Self-advocacy groups and self-audit by housing associations will be telling us this
No-one is living with the NHS as their 'landlord'	DH collected data will confirm this

## **PART THREE**

### **THE WIDER AGENDA**

## 9 Advocacy And Rights

### The Big Headlines

- A new learning disability advocacy development programme including leadership development for national and regional self-advocate leaders
- Every locality should have user led organisations in line with the recommendation in the *Life Chances* strategy

#### 9.1 Where Are We Now?

9.1.1 *Valuing People* made the commitment to include people with learning disabilities in everything about their lives ('Nothing About Us Without Us'). Since 2001, advocacy organisations have grown – the average spend by councils on learning disability advocacy in 2006/7 was £106,000 compared to £74,000 in 2003/4. People with learning disabilities tell us that they are listened to and involved more in decision making about their lives. Self-advocate leadership has been growing, in part through the National Forum of People with Learning Disabilities. Over 60 national and regional self-advocate leaders have participated in leadership development programmes. However, we also know that this progress does not apply everywhere and many people still have little say in even their day-to-day lives.

9.1.2 Other government policies are also strengthening advocacy. *Improving the Life Chances of Disabled People* gave a recommendation that there should be a user led organisation in every locality by 2010. The 'Stronger Local Voice' policy aims to develop local information networks. The Mental Capacity Act 2005 and the Code of Practice published in April 2007 set out a clear legal framework and guidance to empower people who lack capacity, including some people with learning disabilities, to make decisions. It supports families and professionals to put the person at the heart of the decision-making process. There are now powers to help plan ahead for the future by naming an attorney or by making advanced decisions to refuse treatment. People with learning disabilities who have the capacity needed, can be supported to use these powers. For example, this is important for people who might develop dementia.

9.1.3 The legal framework to support people's rights has been strengthened. The Disability Equality Duty requires public sector organisations to take action where the outcomes for people with disabilities are worse than for the wider population. However, we are still some way from these legal rights resulting in real changes in most people's lives.

#### 9.2 Next Steps

9.2.1 People need to be able to speak up and have their voices heard. They need information so they can make good choices. People need to understand their legal rights and how to challenge organisations when those rights are not respected. Those responsible for commissioning and providing services need to listen and respond to the voice of advocacy.

## Advocacy

### 9.2.2 There are different types of advocacy, for example:

- 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.

Self-advocacy should be at the centre of local advocacy strategies, but other types are important, particularly to people with more complex disabilities who may find it harder to speak up for themselves.

### 9.2.3 It is essential that local investment in advocacy continues to grow. This is not just an issue for adult social services. All public bodies have a responsibility to listen and respond to the voice of people who use services and so need to invest in ways (like advocacy) of making this possible.

### 9.2.4 However, it is not just a question of money. Action is needed on:

- the quality of advocacy. Advocacy organisations should be able to demonstrate the positive impact of the money they receive;
- the quality of the leadership of those organisations;
- the ways in which commissioning and providing organisations listen and respond to the voices of advocacy.

### 9.2.5 To help this agenda, the *Valuing People* national advocacy fund will change to focus on supporting advocacy to have a greater impact – rather than pump-priming new groups. This will include self-advocate leadership development, building on the Tomorrow's Leaders programme developed in partnership with the National Forum. This will pay particular attention to people at greatest risk of losing choice and control in their lives, such as those from minority ethnic communities and people with complex support needs.

### 9.2.6 Every locality should have a user led organisations in line with the recommendation in the *Life Chances* strategy - with full involvement of people with learning disabilities. The Department of Health is working with disabled people (including people with learning disabilities), carers and others to take this forward. A new user-led organisations development fund for 2007/08 is available for user-led organisations to apply to deliver user-led action and learning sites up to March 2009.<sup>11</sup>

### 9.2.7 Providing accessible information is essential if people are to have choice and control over their lives and is an implicit expectation of the Disability Discrimination Act. Government will work to improve its performance in this area and expects all other public, voluntary and private bodies to do the same – in particular by employing self-advocacy organisations to advise and develop materials.

### 9.2.8 In order to help use the Disability Equality Duty to improve outcomes from public services, all local learning disability partnerships are asked to hold a specific discussion

---

<sup>11</sup>

[http://www.dh.gov.uk/en/Policyandguidance/Healthandsocialcaretopics/Socialcare/DH\\_076663](http://www.dh.gov.uk/en/Policyandguidance/Healthandsocialcaretopics/Socialcare/DH_076663)



to improve understanding of the DED and consider which areas of local services are falling behind in providing equal outcomes and thus need targeted action in line with DED requirements.

- 9.2.9 Parliament's Joint Committee on Human Rights has been undertaking an inquiry on human rights and adults with learning disabilities. This is expected to report in the near future. Government will fully consider and respond to the conclusions of the Committee.

### 9.3 Action Summary

#### 9.3.1 Nationally:

- a new advocacy development programme to help improve the impact of advocacy;
- around 10 action and learning sites between February 2008 and March 2009 to develop the user led organisation concept.

#### 9.3.2 Locally:

- a clear strategy for learning disability self-advocacy should be developed, covering the commissioning and funding of comprehensive advocacy, and supporting advocacy to increase its effectiveness;
- all partnership boards should focus on the Disability Equality Duty and areas for related action.

### 9.4 Vision Three Years From Now

This will be different.....	We will know this because .....
Investment in learning disability advocacy will continue to have grown, covering the full range of advocacy	Data collected and analysed nationally will continue to show this
Every locality should have a user led organisation that is inclusive of people with learning disabilities	DH will monitor that this happens
The body of self-advocates operating as strong national and regional advocates will have grown	People will be visible, and effective, and even more involved in national, regional and local decision-making

## 10. Partnership With Families

### The Big Headlines

- A Standing Commission on carers to ensure the voice of carers is heard by government
- Updating and extension of the Prime Minister's 1999 strategy for carers
  - A major consultation as to the needs of carers
  - More practical support to be provided to carers
- Support for developing family leadership from the *Valuing People* programme

#### 10.1 Where Are We Now?

10.1.1 *Valuing People* stressed that families are important long-term partners when making the changes expected in *Valuing People*. In some places this has begun to be a reality. The best partnership boards have families as active and equal members. Many of the most innovative changes have had family carers at their centre, for example, the In Control project and much person centred planning. There has been effective planning with and for some people who live with older family carers.

10.1.2 The Government has supported the National Network of Family Carers to become an effective national voice of families of people with learning disabilities. They and other groups and networks, such as Partners in Policymaking, have helped to shape and influence government thinking.

10.1.3 *Our Health, Our Care, Our Say* detailed a range of new and improved commitments to carers including the New Deal for Carers which involves:

- updating and extending the Prime Minister's Strategy for Carers, and encouraging councils and PCTs to nominate leads for carers' services;
- establishing an information service/helpline for carers;
- in each council area, ensuring that short-term, home-based respite support is established for carers in crisis or emergency situations through a £25m per year increase in the carers grant;
- creating an expert carers' programme.

10.1.4 Despite this progress, life for many family carers remains difficult and further action is needed. Families from minority ethnic communities are at greater risk of isolation because of language, culture and religion. Some of this is about direct support to families, such as good carers assessments and short-term breaks. It is perhaps more importantly about the family carer's relative getting the support and changes they want and need. In other words, all of *Valuing People* being delivered so that people (and therefore their family carers) have a better life.

#### 10.2 The Next Steps

10.2.1 Seeing families as a positive asset for change is an essential starting point for the next stage of *Valuing People*.

10.2.2 The Government has recently announced the establishment of a Standing Commission on carers. It will report to the Secretary of State for Health to ensure that the voice of carers is central to the development of government policy.

10.2.3 Further action on family carers includes:

- publication of the extended and revised Prime Minister's strategy for carers in March 2008. It will address key issues that affect family carers' lives including employment, income and equalities as well as health and social care. The strategy is being prepared in partnership with family carers and their representatives;
- £3m per year funding for an information service/helpline for carers that will be in place in summer 2008 and will provide easy access to accurate, up-to-date and relevant information. People from minority ethnic communities are amongst those identified as being a focus for this service;
- £5m a year from 2008 for the expert carers' programme - to provide training for family carers. This will inform them of their rights, available services, develop their advocacy skills and their ability to network with other carers to support their needs individually and as a group.

10.2.4 Nationally, the *Valuing People* programme will continue to invest in and support family carer leadership.

10.2.5 Locally, the actions described in *Valuing People* continue to be important, including:

- forward planning for people living with older family carers;
- providing clear information for families about their rights and services;
- delivering effective carer assessments that recognise the family carers right to a life of their own and the effect that caring often has on their own health;
- innovative short-term breaks, getting beyond bed-based services and making it a positive experience for the person with a learning disability as well as for the family carer;
- considering the needs of people with learning disabilities who are also caring for people themselves – partners, parents and children;
- ensuring family carers are properly supported to be effective partnership board members.

### 10.3 Action Summary

10.3.1 Nationally:

- the establishment of a Standing Commission on carers;
- a comprehensive, cross-government strategy to increase support for carers;
- an information service/helpline for carers;
- a national programme of training, through the expert carers' programme;
- a support programme for family carer leadership.

10.3.2 Locally:

- as the expert carer programme is rolled out, local training should be made accessible;
- actions as outlined in 10.2.4 above.

## 10.4 The Vision For Three Years From Now

This will be different.....	We will know this because .....
The voice of family carers is heard more effectively at national and local levels	Family carers and their organisations tell us this is the case
Good quality carer assessments and services are helping family carers to have their own life and be healthy	Nationally collected and analysed data will tell us this is happening
Support for carers will improve as outlined in the new carers strategy	The new Standing Commission on carers will advise government whether things are improving
Good quality short term breaks and emergency support for families are more widely available	Family carers and their organisations tell us this is the case
Carers will be better informed as to their entitlements – through the support of the information service/helpline	Family carers and their organisations tell us this is the case
Carers will be better enabled to care for themselves, and the person they care for, through the support of the expert carer programme	Family carers and their organisations tell us this is the case

## 11 Including Everyone

### The Big Headlines

- Local planning of *Valuing People Now* should start with people with the most complex support needs
- Compliance with race relations legislation is non-negotiable

### 11.1 Where Are We Now?

11.1.1 Despite lives improving for many people, information suggests that some groups of people are missing out on the changes. This includes:

- some people with the most complex support needs;
- people from minority ethnic communities;
- people on the autistic spectrum;
- people in prison.

*Valuing People* will only be successful when those at the greatest risk of exclusion have benefitted equally from the changes it is making.

### *People with Complex Support Needs*

- 11.1.2 All of *Valuing People* applies to all people with learning disabilities. No matter how complex a person's disabilities, they have the same rights and can expect access to the full range of housing options, paid work, good health, friendships and so on. In some places this has been happening. For example, some In Control pilot projects focused on people with very high support needs and their lives have changed for the better. We know that many people with complex support needs can be supported into paid work.
- 11.1.3 Elsewhere, information suggests that changes are focused on people with less complex disabilities. As a result, for example, some day service change programmes are resulting in people with more complex needs remaining in smaller day centres, doing much the same as they did in the big day centres.
- 11.1.4 Improved infant survival rates and advances in medical technology mean that there is an increasing number of children and (particularly young) adults with very complex health needs. Some of these people are described as 'technology dependent' e.g. reliant on assisted ventilation, artificial feeding. These individuals require a range of primary and secondary health services to meet their needs but recent evidence suggests that this is not always provided.<sup>12</sup> High quality healthcare provision for this group of people should be provided in a way that enables them to lead a fulfilling life in society and not delivered through outdated provision.

### *People from minority ethnic communities*

- 11.1.5 *Valuing People* identified the 'double discrimination' faced by many people with learning disabilities.<sup>13</sup> The *Valuing People* delivery programme has included an ethnicity strand with the provision of guidance, leadership programmes and learning networks. Ethnicity has been an underpinning priority for the LDDF. There has been some progress. For example, surveys show that in 2006, 88% of local authorities had information on the ethnicity of people using services – up from 74% in 2004/5. 52% of partnership boards have been using the LDDF for ethnicity related work – up from 10%. Many more good practice and action examples were reported in 2006 than previously.
- 11.1.6 However, limited action is still a problem. 40% of areas had no information on the ethnicity of children about to enter adult services. Half of Partnership Boards reported no action on Equality Impact Assessments (a legal requirement).

### *People on the Autistic Spectrum*

- 11.1.7 People on the autistic spectrum were covered by the *Valuing People* policy if they also had a learning disability. If they did not, then the policy did not specifically apply. Other policies about disabled people, such as *Improving the Life Chances of Disabled People* and *Our Health, Our Care, Our Say* apply to all people on the autistic spectrum. A clarification note explaining how policy applies to people on the autistic spectrum

---

<sup>12</sup> 'Death By Indifference,' 2007, Mencap

<http://www.mencap.org.uk/html/campaigns/deathbyindifference/reports.asp>

<sup>13</sup> 'Reaching Out', 2006, Mencap:

[http://www.mencap.org.uk/html/ethnicity/reaching\\_out.asp](http://www.mencap.org.uk/html/ethnicity/reaching_out.asp)

*Better services for people with an autistic spectrum disorder*, was issued in November 2006.<sup>14</sup>

### *People in custody and the community*

- 11.1.8 There appears to be a growing number of people with learning disabilities in contact with the criminal justice system. For example, work by the Prison Reform Trust suggests a high number of people with less severe learning disabilities are in prison. Often, these people will not meet the eligibility criteria for adult social care services. The Department of Health intends to work with the prison service to ensure that these people have the necessary support.
- 11.1.9 The Department of Health has recently published a consultation document *Improving Health, Supporting Justice* seeking people's views on a strategy for improving health and social care services for people subject to the criminal justice system. The document has been produced in conjunction with the Ministry of Justice, the Home Office, the Department of Children, Schools and Families and the Youth Justice Board. The purpose of the document is to consult on, and discuss, what more could be done to support people across the criminal justice pathway, including people in contact with the police, the courts, in custodial settings and in resettlement in the community. The consultation document recognises the prevalence and needs of offenders with learning disabilities and the importance of ensuring that those needs are covered in service delivery.

## 11.2 The Next Steps

### *People With Complex Needs*

- 11.2.1 When delivering *Valuing People Now*, there are three important principles:
- start with person centred planning, direct payments and individual budgets for people with the most complex needs – rather than thinking they cannot work. By definition, the more complex a person's support needs, the more individualised support has to be;
  - it is good practice and it works to start with the people with the most complex disabilities first. For example, action on what people do during the day, which will involve changing day services, should start with planning for people with the most complex needs rather than leaving them until last;
  - think what additional services and supports are needed so that people with the most complex needs can be included with everyone else. Do not start by assuming and planning separate services. For example, new ways of working will need places and resources where people with high levels of personal care needs can be supported properly throughout the day and evening.

For people who are described as 'challenging services' these same approaches apply. The Mansell report has recently been reissued and explains how to develop

---

<sup>14</sup> *Better services for people with an autistic spectrum disorder: a note clarifying Government policy and describing good practice*, '2006, Department of Health: [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_065242](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_065242)

individualised services for people who challenge – rather than group services based on people's label or diagnosis.<sup>15</sup>

- 11.2.2 For people with very complex health needs there are some additional steps needed, including:
- PCTs having good information as part of strategic needs assessment to help target specific risk areas e.g. dysphagia, postural care;
  - people having a named health facilitator as part of their person centred planning arrangements;
  - support for family carers, with particular attention to short term breaks and meeting their own health needs & training;
  - robust local plans to make sure that the 'basics' are available to enable people to pursue a fulfilling life e.g. transport, personal care facilities;
  - particular attention to housing strategies, e.g. use of the disabled facilities grant.

- 11.2.3 The Commission for Social Care Inspection have recently carried out work on how services support people with complex needs. We will discuss with them the possibility of repeating this around 2009 to identify if progress has been made.

#### *Ethnicity*

- 11.2.4 All services must comply with the requirements of the Race Relations Amendment Act and public authorities must monitor their work for any adverse impact on race equality. This means that all actions and initiatives described in *Valuing People Now* will need to be assessed for their impact on minority ethnic communities. A similar legal duty applies to disability and gender.
- 11.2.5 A key outcome of this is that local agencies will have information on the ethnicity of people with learning disabilities, their use of public services and the differences between that and usage for the population as a whole. This will enable targeting of initiatives to introduce culturally appropriate services that will achieve greater equality of opportunity and outcome.
- 11.2.6 Nationally, there will be further developments of the learning disability ethnicity leadership programme and regional learning networks. The survey of partnership board progress on ethnicity will be repeated in 2008.

#### *People on the Autistic Spectrum*

- 11.2.7 People with autistic spectrum disorders (ASDs) need support that responds to their individual and specific needs, from staff who have understanding and experience in developing and providing services for people with ASDs. The policy outlined in this document applies directly for those people with autistic spectrum disorders who also have a learning disability. Many of the approaches outlined also work well for people who have higher functioning autism and do not have a learning disability. For example,

---

<sup>15</sup> 'Services for people with learning disability and challenging behaviour or mental health needs,' 2007, Department of Health:  
[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_080129](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_080129)

personalised approaches should be used to commission and provide services, in line with good practice described in *Better services for people with an autistic spectrum disorder*.

### *Offenders in Custody and the Community*

11.2.8 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 there should be health screening programmes that identify their learning disability, physical and mental health issues and enable access to appropriate education and rehabilitative programmes. Good practice guidance has been produced for people working in the criminal justice system on how to work with and support people with learning disabilities<sup>16</sup>. The health and social care in criminal justice programme will continue to promote the use of this good practice.

11.2.9 DH guidance to support commissioners of forensic learning disability services will be published soon. To help identify offenders who have a learning disability at an early stage, a screening tool is being tested for use across the criminal justice system. This will help trigger appropriate services within the prison system and on discharge, with the aim of targeting community services to break the cycle of re-offending.

### 11.3 Action Summary

#### 11.3.1 Nationally:

- ethnicity will continue to be a central part of the national *Valuing People* delivery programme;
- DH will consider extending the appointment of its part-time advisor on autism, subject to funding;
- learning disability to be included in the delivery programme around prison health;
- forthcoming good practice guidance for commissioners of forensic services for people with learning disability.

#### 11.3.2 Locally:

- local delivery partners should have an early, person centred focus on people with complex needs in service change programmes;
- local agencies should fulfil obligations in the Race Relations Amendment Act, including developing data about people from ethnic minority communities;
- local delivery partners should action the autism 'clarification note';
- PCTs should use the good practice guidance on commissioning forensic services for people with learning disability when it is produced;
- PCT's should ensure prison health initiatives are inclusive of prisoners with learning disability in line with disability equality legislation.

---

<sup>16</sup> [Positive Practice: Positive Outcomes: A Handbook for Professionals in the Criminal Justice System working with Offenders with Learning Disabilities](http://www.kc.csip.org.uk/viewresource.php?action=viewdocument&doc=98519&grp=1) 2007. Care Services Improvement Partnership:  
<http://www.kc.csip.org.uk/viewresource.php?action=viewdocument&doc=98519&grp=1>



#### 11.4 The Vision For Three Years From Now

This will be different.....	We will know this because .....
People with complex needs are not being 'left behind' in traditional services	Reviews and inspections by regulatory bodies will tell us this
Local learning disability partnerships will have and use good information on people from minority ethnic communities to deliver culturally appropriate services	We will repeat the survey of partnership board work on ethnicity
Local services will be able to demonstrate a narrowing of the gap in service uptake between people from minority communities and the wider population	Data from the PSA indicators on employment and housing could be analysed by ethnicity by local authorities
Local clarity about responsibility for services and supports to people on the autistic spectrum so people are not falling between services	People with ASD and their family carers will be able to report an improvement in the services that they receive
People with learning disabilities in contact with the criminal justice system will increasingly be supported by services and staff with knowledge and competence in learning disability	People with a learning disability in contact with the criminal justice system will tell us that this is the case

## 12 People As Local Citizens

### The Big Headlines

- Stopping hate crime against people with learning disabilities is a new part of the *Valuing People* policy
- The Home Office will produce good practice guidance to help in reporting, dealing with and stopping hate crime against people with learning disabilities
- The Department for Transport will work to ensure that transport initiatives are benefitting people with learning disabilities
- A greater focus on supporting person relationships by care managers and service providers
- Parents with a learning disability will benefit from wider government initiatives to support parents

### 12.1 Hate crime

#### 12.1.1 Where Are We Now?

12.1.1.1 Many people with learning disabilities tell us they do not feel safe in their local communities. They face hate crime, often from young people, that is targeted at them because of their disability. This ranges from being called names through to physical assault. There have also been a small number of recent cases where people with a learning disability were murdered – it appears in part because of their learning disability. The original *Valuing People* document said nothing about hate crime. Government has recently become more aware of the problem thanks to the National Forum of People with Learning Disabilities, which has been leading a campaign for action on hate crime.

#### 12.1.1.2 The main issues and challenges are:

- reporting crime when it happens. Many people with learning disabilities find it difficult to report crime because police processes can be inaccessible or unwelcoming. There are good examples of dealing with this, like having easy read reporting forms and training peer advocates to support people as they report a crime;
- making hate crimes against people with learning disabilities visible. Hate crime data generally does not identify that a person with a learning disability was the victim. This means the police and local crime and disorder reduction partnerships do not realise what a problem hate crime against people with learning disabilities is, because they do not see it recorded;
- improving the response from the criminal justice system. Staff do not always know how to respond to a person with a learning disability and often people who report hate crimes say they were not taken seriously. Staff training, delivered by people with a learning disability, is one way of helping to address this;
- making sure people get justice. Often, when a person with a learning disability reports a hate crime, the matter is referred to adult protection procedures and not treated as a crime. Whilst adult protection might be appropriate, people have the same rights as every other citizen to justice through the criminal justice system.

### 12.1.2 The Next Steps

12.1.2.1 Taking action to address hate crime and help ensure people feel safe in their local communities is an important challenge to be addressed both locally and nationally.

12.1.2.2 The Home Office, in partnership with the Department of Health, will produce guidance for the criminal justice system and local authorities addressing the issues identified above. The Home Office are also funding two voluntary sector initiatives:

- “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.
- Distribution of the PIP pack, a pack designed by self advocates to raise awareness of hate crime and personal safety.

### 12.1.3 Action Summary

12.1.3.1 Nationally:

- good practice guidance will be published to help address the issues identified above;
- Home Office grants will support voluntary sector initiatives on hate crime.

12.1.3.2 Locally:

- learning disability partnerships working together with crime and disorder partnerships to use the national guidance, to include people with learning disabilities in community safety strategies and other local work that will identify, respond to and stop hate crime against people with learning disabilities.

### 12.1.4 The Vision For Three Years From Now

This will be different...	We will know this because ...
Hate crime against people with learning disabilities is being properly addressed in every local area	Data on hate crime is being collected and reported Community safety strategies cover people with learning disabilities Criminal justice system disability equality strategies cover people with learning disabilities
People feel confident reporting hate crime, believing action will be taken	Self-advocacy organisations tell us things are improving The data collected tells us action against hate crime is being taken

## 12.2. Transport

### 12.2.1 Where Are We Now?

12.2.1.1 Transport and mobility have a major influence on most people's lives, connecting people to jobs, services and social networks. Poor or inaccessible transport can prevent

people from being part of society. We know that people with learning disabilities are less likely to make journeys than non-disabled people, and are more likely to be unable to get a job because of travel difficulties.<sup>17</sup>

12.2.1.2 The Government has made some good progress towards an accessible public transport system. For example, the Disability Discrimination Act requires all new trains, buses and coaches to be accessible to disabled people. Over a third of all trains, together with half of the bus fleet, have end dates set for full accessibility. Since December 2006, it has been illegal for transport operators to discriminate against disabled people or fail to make a reasonable adjustment.

12.2.1.3 However, action has largely focused on physical access. People with learning disabilities face additional barriers, in particular the lack of accessible information and staff attitudes. In relation to this:

- the Department for Transport (DfT) is working with GoSkills (the sector skills council for passenger transport) and others to encourage transport operators to offer and improve disability awareness training, which is part of GoSkills' NVQ programmes for drivers;
- DfT and the Disabled Persons Transport Advisory Committee (DPTAC) will produce guidance material to the transport industry;
- DfT has recently reviewed travel training schemes, including those aimed at people with learning disabilities, and will shortly be publishing the outcome of this;
- DfT has produced best practice guidance for transport providers on the provision of information for disabled people, *Inclusive Mobility*<sup>18</sup>

12.2.1.4 Local transport planning needs to consider the broad range of accessibility issues for people with learning disabilities. In addition to the above issues, this also considers whether the transport system helps people access key services such as healthcare, education and jobs. Accessibility planning is required as part of producing local transport plans. The 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.<sup>19</sup>

## 12.2.2 The Next Steps

12.2.2.1 Locally, learning disability partnership work on transport should be focused in part on influencing the local transport plan. Advice has been produced by the VPST on effective ways of doing this. Local action will also need to address:

- the range of support people need to travel, such as travel training and having a vehicle to meet personal mobility needs
- the issues and costs around having a supporter travelling with them
- the problem of safety and hate crime on transport (see para 12.1)

---

<sup>17</sup> *Secondary analysis of existing data on disabled people's use and experiences of public transport in Great Britain: A research report for the Disability Rights Commission*, Jollie, Priestley and Matthews, Centre for Disability Studies, 2006. Available from [www.drc-gb.org/docs/Transport\\_Campaign\\_Research\\_Report.doc](http://www.drc-gb.org/docs/Transport_Campaign_Research_Report.doc).

<sup>18</sup> [www.dft.gov.uk/transportforyou/access/tipws/inclusivemobility](http://www.dft.gov.uk/transportforyou/access/tipws/inclusivemobility)

<sup>19</sup> [www.dft.gov.uk/pgr/regional/ltp/guidance/fltp/accessibleformatsforlocaltra3655](http://www.dft.gov.uk/pgr/regional/ltp/guidance/fltp/accessibleformatsforlocaltra3655).

12.2.2.2 DfT will work with the *Valuing People* delivery programme to audit whether current transport initiatives are effectively addressing the needs of people with learning disabilities and then take additional action as needed. For example:

- the inclusion of learning disabilities within disability awareness training
- the content of DfT's own best practice guidance
- DfT guidance on accessibility planning for local transport plans, to ensure that local authorities consider the needs of those with learning disabilities in light of the introduction of the disability equality duty

### 12.2.3 Action Summary

#### 12.2.3.1 Nationally

- DfT and the *Valuing People* delivery programme to 'audit' national actions to ensure their inclusion of people with learning disabilities

#### 12.2.3.2 Locally

- learning disability partnerships should engage with local transport plans to ensure the effective inclusion of people with learning disabilities

### 12.2.4 The Vision For Three Years From Now

This will be different.....	We will know this because .....
The transport needs of people with learning disabilities will be clearly included in local transport plans	DfT and GO reviews of transport plans will confirm this
People feel more confident about using public transport and are finding it easier to get about	Self-advocacy organisations tell us this is the case

## 12.3 Relationships

12.3.1 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 have very limited relationships. For example, a national survey showed that 31% of people had no friends and 5% of people had neither contact with friends nor with their family. There are many reasons for this, including:

- the way in which professionals take decisions about service delivery that ignore existing relationships and break up friendship patterns, for example 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
- many people still not recognising and accepting that people with learning disabilities, like anyone else, want and need personal and sexual relationships

- 12.3.2 Promoting personal relationships is not something that central government has a direct role in, but is something that local commissioners and service providers should pay greater attention to. This should include:
- listening to what people say they want and need in terms of relationships in their lives through their person centred plans
  - giving full consideration to maintaining and supporting relationships in decisions about both individual services and strategic planning including support around relationships and sex education
  - organising service provision in a way that helps people's social contacts e.g. not designing shift patterns that curtail people's social lives
  - considering giving support to voluntary sector initiatives that promote full social lives and networks
  - being sensitive to different approaches from different cultural groups
  - positively supporting same-sex relationships where that is the choice of people

## 12.4 Parents with a Learning Disability

### 12.4.1 Where Are We Now?

12.4.1.1 *Valuing People* highlighted the need for services to support parents with a learning disability as did the Treasury and Department for Children, Schools and Families' Children and Young People Review<sup>20</sup> and the Social Exclusion Task Force.<sup>21</sup> This included a commitment that parents with learning disabilities and their children would benefit from all initiatives aimed at supporting parents and children.

12.4.1.2 The Department of Health and DfES (now the DCFS) have jointly issued good practice guidance on working with parents with learning disabilities. The Social Care Institute for Excellence have carried out a knowledge review and developed a resource guide for joint working across children's and adults' services to support disabled parents.

12.4.1.3 There is clear evidence that there are increasing numbers of parents with a learning disability in contact with services. Most are experiencing a range of difficulties, including poverty and social isolation. There is some evidence that such parents are at a disproportionate risk of losing their children into care. Parents and their children often continue to fall between children's and adults' specialist services, whilst mainstream services sometimes struggle to meet their needs. Research evidence illustrates a need for independent advocacy.

### 12.4.2 The Next Steps

12.4.2.1 The joint good practice guidance has started to be disseminated within adult learning disability services and this now needs to happen within children's social care and mainstream health services.

---

<sup>20</sup> 'Aiming High for Disabled Children: Better Support for Families,' 2007, HMT/DCSF: [http://www.hm-treasury.gov.uk/media/C/2/cyp\\_disabledchildren180507.pdf](http://www.hm-treasury.gov.uk/media/C/2/cyp_disabledchildren180507.pdf)

<sup>21</sup> [http://www.cabinetoffice.gov.uk/social\\_exclusion\\_task\\_force.aspx](http://www.cabinetoffice.gov.uk/social_exclusion_task_force.aspx)

12.4.2.2 The government has a significant programme of work aimed at supporting parents generally, and a range of programmes aimed at groups of parents experiencing particular difficulties. Parents with learning disabilities must have access to the same level of information and advice that is intended for all parents. Action will be taken to ensure that some of the more targeted interventions are properly inclusive of parents with learning disabilities.

12.4.2.3 The Department for Children, Schools and Families is supporting local authorities to improve the commissioning of parenting support, ensuring provision for the full range of local need with accessible support for parents through extended school and Sure Start children's centres. This will include an action research project – the Parenting Implementation Project – with families with parents with a disability, including those with a learning disability as part of the target group.

### 12.4.3 Action Summary

#### 12.4.3.1 Nationally

- the Department of Health and Department for Children, Families and Schools will ensure that information they publish aimed at parents is available in accessible formats
- the Care Services Improvement Partnership will work with relevant government departments and the Working Together Network to disseminate the existing good practice guidance, alongside the SCIE resource guide

#### 12.4.3.2 Locally

- adult and children's services, supported by learning disability partnerships, should work together to use and implement the content of the good practice guidance
- inter-agency parenting support initiatives should be inclusive of parents with a learning disability

### 12.4.4 The Vision For Three Years From Now

This will be different.....	We will know this because .....
More parents and their children will be receiving appropriate support, resulting in a smaller percentage of children of parents with a learning disability being subject to care orders	Parents will say that they are getting all the support and information that they need
Children's and adults' health, education and social care services will be working together to provide personalised support to parents with learning disabilities and their children	Local services will report better joined up working, with parents feeling more supported

## 13 Making The Transition To Adulthood A Positive Experience

### The Big Headlines

- A £19m Transition Support Programme, part of which will be used to promote person centred approaches in transition
- A focus on young people in transition for all aspects of *Valuing People Now* (i.e. jobs, housing individual budgets ...)

#### 13.1 Where Are We Now?

13.1.1 Families and young people still say the transition from children's to adult services is the most difficult time in their lives and that they feel excluded from decisions. The outcomes are often segregated services rather than helping them to achieve the same things as other young people, i.e. an education, a job, and living with their friends in their local community.

13.1.2 To help deliver the promise in the children's national service framework, the person centred transition project has been introducing person centred approaches into the statutory transition planning process. The programme is open to every authority in the country and over 300 year 9 and 200 year 10 children have experienced person centred reviews. 350 people have been trained to facilitate person centred reviews with young people. 12 schools are exploring how to integrate person centred approaches into the curriculum. Parents and young people say they feel really involved for the first time and outcomes for people are beginning to change. The further education (FE) sector is now joining in. DH and DCSF will continue to support this initiative.

#### 13.2 The Next Steps

13.2.1 We know the problems with the transition process and we know what is needed to make things work. The challenge is to make that happen. Government has recently announced new funding around disabled children. 'Aiming high for disabled children' has a clear commitment for consolidation of the person centred planning process from age 14 as part of the £19m transition support programme. This will include working across agencies and with adult services and the use of person centred approaches.

13.2.2 In the longer term the government intends to build on the 14-19 transition support programme and identify ways to improve practice to support transition from childhood to adulthood between 14 and 25.

13.2.3 The Department of Health is publishing good practice guidance for health professionals and their partners in planning the transition of young people from paediatric care to adult services. It has also established a network of health professional champions who will promote good transition planning in partnership with other agencies and young people and families.

13.2.4 A focus on young people moving into adulthood is an important part of *Valuing People*. Stopping young people moving into outdated traditional services as they leave school and home is an effective way of changing the whole service system. Young people in transition should always be a focus and target for early action when developing



strategies to support people into paid work, access ordinary housing, introduce individual budgets and undertaking comprehensive health checks.

### 13.3 Action Summary

#### 13.3.1 Nationally:

- the person centred transition project will be extended and expanded

#### 13.3.2 Locally:

- every local area should have a multi-agency transition strategy, led by senior officer, and supported by an implementation group involving all key stakeholders, in particular young people and their families
- involvement in the person centred transitions initiative should be the norm
- young people in transition should be a focus for all *Valuing People Now* delivery actions

### 13.4 The Vision For Three Years From Now

This will be different.....	We will know this because .....
Every young person with a learning disability and with a 'statement' will have person centred reviews from the age of 14 to 19	Young people will tell us that they are feeling more supported and are having a real say about their future
The Year 9 review will produce a person centred transition plan that will inform the commissioning and provision of future services and supports, be reviewed each year, and be at the core of a smooth transition to adult services	Evaluation of the Transition Support Programme will tell us this is happening
Young people will leave school and enter paid work and education in far greater numbers than at present	The numbers of young people recorded as 'not in education, employment or training' will show this reduction
A substantial increase in the number of young people taking up individual budgets and direct payments	Nationally collected and analysed data will tell us this

## 14 **Improving The Workforce**

### **The Big Headlines**

- Action led by the adult social care workforce strategy board to review learning disability workforce issues
  - National and local action to increase take up of the learning disability qualification
  - Local training to ensure a focus on skills to support choice, control and social inclusion

## 14.1 Where Are We Now

- 14.1.2 There are many talented and skilled staff working in services. We also know that the quality of staff skills is a problem in some places. The Healthcare Commission reports into abuse identified very poor staff practice that basic training and education should have addressed.
- 14.1.1 The personalisation agenda means that some big changes will be needed in the workforce. As people take more control over their lives and services, staff will need to be trained, organised and managed in different ways. Different job roles will be needed, filled by staff with different skills, with new roles that support people into paid work, integrated arts and new jobs around advocacy and service brokerage.
- 14.1.3 A number of initiatives are helping to change the social care workforce. These include:
- the Secretary of State for Health commissioning work to improve the status of social care, including the development of a skills academy to focus on leadership, management and commissioning
  - the national social care recruitment campaign
  - DH establishing an adult social care workforce strategy board to take forward the status of social care review
  - Skills for Care taking responsibility for developing the learning disability awards framework into a new learning disability qualification (LDQ), which is an important tool in improving staff practice for front line staff. 38,000 staff have achieved the LDAF induction/foundation, but take up of wider LDAF units has been disappointing for such an excellent qualification
- 14.1.4 Education and training for health professionals working in the learning disability field – nurses, psychologists, psychiatrists, speech and language therapists - faces similar challenges. New guidance from the Chief Nursing Officer will make recommendations about the future of learning disability nurse training. Health professionals in general (health visitors, midwives, GPs, and others) also need an understanding of how to make their services accessible to people with learning disabilities. Beyond that, training for the wider community in learning disability awareness – such as shop assistants, the police, bus drivers and bank workers – is needed to help society understand more about serving people with a learning disability.

## 14.2 The Next Steps

- 14.2.1 Nationally, Ministers have undertaken to review learning disability workforce issues following the Healthcare Commission abuse reports. This work will be coordinated by the national learning disability workforce group – reporting to the new adult social care strategy board and linking into DH NHS workforce structures.
- 14.2.2 The adult social care workforce strategy board, skills academy and the status of social care review will all ensure that particular attention is paid to learning disability workforce issues.
- 14.2.3 Skills for Care (in partnership with Skills for Health and the Children's Workforce Development Council) have set up a 'New Types of Worker' (NToW) programme. It aims to help change the workforce in response to policy changes such as individual

budgets and the social inclusion agenda. NToW has a grant and a research programme. Both of these are funding learning disability initiatives, for example building on earlier research with people with learning disabilities to change job descriptions and person specifications. NToW has also developed a strategic partnership with the In Control team, exploring issues arising for staff from a person centred service.

14.2.4 Skills for Care's leadership of the LDQ will include a partnership with the *Valuing People* delivery programme to promote increased take-up of LDQ – in particular beyond induction modules. Work will take place to ensure a continued focus on achieving LDQ in the performance and regulatory framework.

14.2.5 Locally, partnership boards were asked to develop workforce plans in 2002. Now would be an appropriate time to review those in the light of the personalisation agenda.

14.2.6 Training should reflect the needs and life aspirations of the people that staff are supporting. Training sometimes only focuses on basic 'technical' issues such as lifting and handling and fire safety. Although these are important, equally so is training that promotes an understanding of person centred planning, advocacy and rights, working with family carers and community inclusion. Additional training should be designed around the individual, for example covering specific health conditions, culturally appropriate support, autism and communication techniques as appropriate. Good staff training often involves people with learning disabilities and family carers as paid trainers.

### 14.3 Action Summary

#### 14.3.1 Nationally:

- the Department of Health will review learning disability workforce issues in the light of recent abuse reports, including a learning disability focus within the new social care workforce initiatives
- Skills for Care will lead on the further development and take-up of the learning disability qualification

#### 14.3.2 Locally:

- workforce planning should be reviewed in the light of the developing *Valuing People* agenda
- people with learning disabilities and family carers should be employed as paid trainers on staff training programmes
- the content of in-service training for staff content should be widened to cover the 'whole life' agenda of *Valuing People*.

#### 14.4 The Vision for Three Years From Now

This will be different.....	We will know this because .....
All new staff will have completed the LDQ induction award within 12 weeks of commencing employment, (in line with National Minimum Standards) and there will be significantly increased take-up of the LD qualification	LDQ accreditation bodies and registration and inspection procedures will confirm this.
LDQ modules will be used by generic staff (police, leisure commercial etc) to promote general disability awareness	LDQ accreditation bodies and registration and inspection procedures will confirm this
The content of health professional training will demonstrably be in line with the <i>Valuing People</i> agenda	People using services will encounter staff with a greater understanding of learning disability

## **Part Four**

### **The Biggest Priority**

### **Making it Happen**

## 15 Providing The Right National And Local Leadership And Support

### The Big Headlines

- The national support structures to help make *Valuing People* happen will continue for another three years, with a number of changes
- The Learning Disability Development Fund (LDDF) will continue and will be paid directly to local authorities
  - The old long stay census will cease
- Partnership boards are to continue, with consideration being given to increasing the requirements on statutory bodies to consult with them and an increased programme of support to strengthen their impact.
  - A renewed *Valuing People Now* awareness campaign

### 15.1 Where Are We Now?

15.1.1 *Valuing People* included national and local leadership and support arrangements to help make *Valuing People* happen:

- the **National Forum of People with Learning Disabilities** has played an important role and has influenced government policy on important matters. By using the nine regional fora attended by many local self advocates, they offer government a representative view of people with learning disabilities;
- the **National Learning Disability Task Force** provides a place where national leadership in learning disability can come together to review progress and report to government on what needs to be done;
- the **National Director of Learning Disabilities** has a central role, both inside and outside government, in ensuring the learning disability agenda is taken forward. Since 2006, this role has been partly carried out by a person with a learning disability;
- local, regional and national delivery support has come from the ***Valuing People Support Team*** (now part of CSIP). The clear view expressed to government is that without the VPST, progress would have been much less;
- the **Learning Disability Development Fund (LDDF)** has provided funds to help local delivery by meeting some change management costs. Local authorities and others have clearly stated that the LDDF has been an important help to change;
- **Learning disability partnership boards** are the local multi stakeholder vehicle for delivering *Valuing People*. At their best, boards have been a positive force for change and have shown how people with learning disabilities and families can be effectively involved in important decision-making. However, some partnership boards have been ineffectual.

### 15.2 Next Steps

15.2.1 The renewed focus of *Valuing People Now*, means that a continued national and regional support programme is essential. However, five years on, it is also appropriate that some of the arrangements change.

15.2.2 The Government will:

- continue to support the National Forum for a further three years. During that period, discussion will be held with the National Forum about how it will secure its future, and funding, beyond that date;
- continue to support the Task Force for a further three years. However, title 'task force' does not reflect its role, which is to review progress on *Valuing People* and make recommendations to government on learning disability issues. Its title and membership will thus be reviewed with effect from April 2008.

15.2.4 A ministerially-led cross-government group, currently the 'learning disability programme board', will meet regularly to report on progress to delivering the national priorities of *Valuing People Now*.

15.2.4 The national director role will continue for a further three years, including the employment of a person with a learning disability within the role. The detail of the role will be reviewed including strengthening its involvement with all government departments.

15.2.5 For the next three years, delivery support to the field will be through two different but related elements:

- Support to develop the capacity and performance of local and regional people, including local learning disability partnerships will be provided through *Valuing People* regional advisers - linked to the government offices of the regions;
- specific support over the key national priorities identified in *Valuing People Now*, will be provided through a small *Valuing People* team - led by the National Director. With the aim of focusing attention on the key priorities, they will liaise with government and other national bodies, develop good practice materials and other supports and promote their local and regional use in partnership with the *Valuing People* regional advisers.

The precise organisational arrangements for this support will be determined once the review of CSIP and the regional presence of the Department of Health is completed.

15.2.6 The LDDF will continue for a further three years with an important change. In recognition of the lead role of local authorities on learning disabilities, the money will be paid directly to local authorities (rather than through PCTs) to support local authorities to delivering the key outcomes for people with learning disabilities within the national indicator set. This includes indicators on employment and settled accommodation for people with learning disabilities, and on tackling health inequalities.

15.2.7 A significant part of learning disability funding comes through an allocation called the old long stay (OLS) fund. Originally linked to people admitted to long stay hospitals before 1971, this money goes to PCTs, most of which is then transferred to local authorities. Annual allocations are based on a regular census. The benefits of the OLS system (i.e. a better distribution of funding across the country) no longer outweigh the problems caused by holding the census and moving money around. The OLS learning disability census will therefore end with immediate effect and the allocation be consolidated in PCT budgets and considered as part of overall PCT spend on learning disabilities for the transfer purposes described in section 16.

## *Partnership Boards*

- 15.2.8 In preparing *Valuing People Now*, a strong message to government has been that partnership boards need to continue, but they need to be more influential. People say they need more ‘teeth’.
- 15.2.9 Consideration has been given to a number of ways of giving greater power to partnership boards. They are not statutory bodies and so it is not appropriate to give them formal authority over mainstream public budgets. There are other decision-making processes for these budgets, including democratically elected local government.
- 15.2.10 However, government does expect other bodies - in particular local government and the NHS - to consult with Partnership Boards as their main source of information when planning and taking decisions that affect the lives of people with learning disabilities. Many local authorities and PCTs have not been doing this. We will therefore give further consideration to how all public bodies can be encouraged to use and work with partnership boards, including by:
- considering the potential for introducing a statutory requirement on them to consult partnership boards;
  - specifically referring to learning disability partnership boards in relation to the new statutory duty contained in the Local Government Bill to involve, inform and consult communities.
- 15.2.11 Partnership boards should link in with the local strategic partnership (LSP) for their area. The LSP develops a sustainable community strategy which in turn is set down in a local area agreement. This will identify local priorities with specific targets, agreed with the government office. The Local Government and Public Involvement in Health Bill<sup>22</sup> requires local authorities and PCTs to prepare a joint strategic needs assessment of the health and well-being needs of the local population. This joint strategic needs assessment will, for reasons of good practice and meeting legal requirements of the Disability Equality Duty, need to consider people with learning disabilities. Local learning disability partnerships should be consulted on, and get engaged with the strategic needs assessment process. The joint strategic needs assessment will also influence wider planning and commissioning decisions of local government and the NHS.
- 15.2.12 Some partnership boards are very effective. The VPST has published advice on being an effective partnership board. If all partnership boards fully followed this advice, Boards would be more effective and influential. One problem is that some partnership boards hardly exist outside the formal meeting. It may be more helpful for people to think of the **local learning disability partnership**, which exists all year around, and meets every few weeks as a board to discuss and review its work, rather than just think about the partnership board as a meeting.

---

<sup>22</sup> The Local Government and Public Involvement in Health Bill is expected to receive Royal Assent in the autumn 2006.



<b>Effective partnership boards.....</b>	<b>Weak partnership boards.....</b>
Concentrate on developing partnerships all year around	Hardly exist outside partnership board meeting
Link into local strategic partnerships and inform local area agreements	Operate in isolation
Start from a person centred approach, thinking about life outcomes for people	Are more concerned with the process of meeting
Are properly supported and resourced to do their job well	Exist by people squeezing it into other responsibilities
Are co-chaired by a senior elected executive member of the local authority and a person with a learning disability (and/or family carer)	Are chaired by a learning disability manager or someone at social services assistant director level or below
See themselves as an expert resource to mainstream services to help them understand how to include people with learning disabilities and then negotiate agreements on how this will be done	Sees people from mainstream services as problems who do not turn up to meetings
Properly support and resource self advocates and family carers to be influential members of the board	Self advocates and families are marginalised in meetings
Self advocates, families and the voluntary sector are elected by wider constituencies and then supported to communicate back to the people they are representing	Self advocates, families and the voluntary sector are selected or appointed by the local authority with no communication with wider people
Have meetings that are an event, with a range of techniques used to discuss and deal with issues	Use traditional committee meeting structures
Publicise accessible meetings and minutes	Have private meetings and people do not know what is going on
Set themselves clear objectives and publicly report on what it has achieved (including to the council overview and scrutiny committee and local strategic partnership)	Have no performance culture and never questions their own effectiveness

15.2.13 People with learning disabilities and families who know about *Valuing People* are almost always supportive of it. However, many people and their families know little about the policy and what it says they can expect. Unless they know this, they are unlikely to demand change. Consideration will therefore be given to an awareness campaign, possibly through some form of simple ‘pledge card’ for local distribution that outlines the key principles and outcomes from *Valuing People*.

### 15.3 Action Summary

#### 15.3.1 Nationally:

- continued funding and redesign of the national support structures;
- continuation of the LDDF but with it being paid directly to local authorities;
- further clarification on the role of partnership boards in guidance in the spring;

- *Valuing People* regional advisors will prioritise supporting best practice reviews of all Partnership Boards in 2008;
- government will discuss with CSCI the potential for both targeted and general reviews of partnership board effectiveness;
- a new *Valuing People Now* awareness strategy.

#### 15.3.2 Locally:

- All local learning disability partnerships should review their board membership and working practices with a view to (i) ensuring the board is properly consulted by statutory agencies (ii) operating in line with good practice advice (iii) ensuring sufficient resources for the operation of the board;
- learning disability partnerships should report annually (for example to Overview and Scrutiny Committees and LSPs) on achievements and future plans;
- LDDF spending decisions should be taken by the local authority as recommended by the Partnership Board and in line with the priorities contained in this document.

#### 15.4 The Vision for Three Years From Now

This will be different.....	We will know this because .....
Learning disability partnerships in <u>all</u> parts of the country will be effectively influencing decisions about the planning and delivery of public services	Partnership boards will tell us this and CSCI reviews will confirm it
LDDF will be fully used across <u>all</u> the country in line with the national indicator set	Nationally collected and analysed data will confirm this
Significant progress will have been made on all priority areas in <i>Valuing People Now</i>	All the ways described elsewhere in this report will have confirmed it

## 16 Better Commissioning

### **The Big Headlines**

- Funding and commissioning responsibility for learning disability ‘social care’ services will transfer from the NHS to local government
- Work to fully assess the impact of population changes on demand for learning disability services
- The only reason a person with a learning disability should be an in-patient in an NHS or private sector hospital bed is if they are receiving an active programme of assessment or treatment prior to moving back home to their local community

#### 16.1 *Commissioning*

- 16.1.1 It is the role of the commissioner to ensure that people get the best outcomes possible from public money. They are, in effect, there to ‘champion’ the interests of the population and individuals. The main actions of commissioners – from the production

of strategic needs assessments through to individual purchasing decisions, should always be based upon this important starting point.

- 16.1.2 Individual budgets and direct payments will have a big impact on commissioning as people take control of their own purchasing decisions. However, commissioners will continue to have a vital role, both for commissioning services for people who have not taken direct control of their funding and also in helping to ensure (for those that have) the availability of an appropriate range of supports and opportunities from which they can commission their own support.
- 16.1.3 The recently announced Socially Excluded Adults PSA is key to delivery for this group. In commissioning improved and comprehensive services for people with learning disabilities, commissioners should consider the implications of the PSA for commissioning and local delivery.
- 16.1.3 There are some particular issues for learning disability commissioning that need attention. This section considers the three issues of :
- commissioning responsibility;
  - funding and resources;
  - local services for local people.

## 16.2 *Commissioning Responsibility*

- 16.2.1 Transferring responsibility for learning disability services (other than mainstream healthcare) to local authorities started in 1971. In the 1990s, policy stated that, as people left the institutions, commissioning responsibility and the associated resources should be transferred to local authorities – with financial transfers continuing after the deaths of former hospital residents in order to help meet the costs of a new generation of people who in the past would have entered institutional NHS care. *Valuing People* re-stated these commitments and the Health Act flexibilities in 2001 brought in new legal powers to pool budgets and provide for local authority ‘lead commissioning’.
- 16.2.2 In many places, these changes have been made and successful local authority led partnerships are improving services. Elsewhere, this is not the case, or the annual negotiations over financial transfers cause unnecessary difficulties.
- 16.2.3 In order to ensure that the resources for commissioning learning disability services rest with the authority with lead responsibility, PCT learning disability budgets and the associated commissioning responsibility, will transfer to local authorities. The transfer will not include that for either mainstream/general healthcare nor forensic/offender services. The proposal is that specialist learning disability healthcare commissioning will remain with PCTs and should be commissioned in partnership with the local authority, potentially using the Health Act flexibilities.
- 16.2.4 Local authorities and PCTs will be required to agree an appropriate amount for transfer which will then be allocated by government, if possible in 2009/10, but based upon spend in 2007/8. Further detail on how this will be achieved will be announced shortly.
- 16.2.5 This change will provide greater certainty about resources for learning for specialist social care services where the lead responsibility rests – with local government – and

allow the NHS to focus fully on its primary learning disability responsibility i.e. equal access to good quality healthcare.

### *16.3 Money and Resources*

- 16.3.1 Spending on social care for adults with learning disabilities (at 2005/6 prices excluding Supporting People) has increased from approximately £1.5 billion in 1995/6 to approximately £3 billion in 2005/6. This mainly arises from changes in the population. Since the early 1980s, more babies have been surviving birth with complex disabilities. These young people are now entering adult services. Also, people are living longer – in particular people with Down’s syndrome. Finally, there is evidence of higher levels of learning disability amongst some South Asian communities.
- 16.3.2 Added to this, people and their families now have higher expectations about their lives than thirty years ago when institutionalised support was the norm. All this adds pressure to public resources.
- 16.3.3 The Comprehensive Spending Review (CSR) settlement for local government recognises the full range of pressures facing the sector. This includes the impact of demographic change on demand for, and complexity of, social care services - including learning disabilities. The way of calculating this has been widely discussed with the Local Government Association and Association of Directors of Adult Social Services. As with all public services, the CSR also seeks to ensure the best value for money in all local government services, so resources can be freed up to invest in new priority areas.
- 16.3.4 Data about the increasing demands on learning disability services is not as well researched as for other populations and service areas. We will explore, with other partners, how to develop a better understanding of these demands and their implications between now and the next spending review in order to properly inform future spending decisions.
- 16.3.5 In the meantime, commissioners should make the best use of current resources. This includes:
- inter-agency partnership. It is policy that no one part of government should pass responsibilities to another without the associated funding. Para 16.2.1 outlines specific policy about this in relation to learning disabilities which expects the maintenance of NHS investment levels as responsibilities transfer. This is the expectation both for immediate local negotiations and the commissioning and financial transfer outlined in para 16.2 above;
  - data. Having accurate information on numbers of people - including future changes and broad data on need, for example through an effective and accurate multi-agency register should be one starting point for budgetary decision-making.
  - personalisation. The evidence from the In Control pilots is that individualised services, based on what people want, cost the same – if not less - than traditional services. An analysis of council spend by CSIP<sup>23</sup> also shows that those councils who commission more individualised services achieve better outcomes for people at no additional cost, compared to council’s who purchase the greatest

---

<sup>23</sup> Commissioning for Adults with Learning Disability: A Tale of Two Nations: 2007, CSIP

proportion of traditional and residential care services. When faced with increasing demand and financial constraints, commissioners should not resort to traditional group services, but focus even more on individualisation;

- efficiency. Making use of systematic approaches to quality and costing of residential and supported housing services with a view to increasing value for money and, where possible, releasing funds for use on self-directed support. A national tool to support this is being piloted and will be available in 2008;
- use of these tools, when developed, will be important in the short to medium term. Our strategy is to decommission specialised regional services wherever possible with a direction towards housing and personalised service solutions at a local level. At a regional level, local authority commissioners may also wish to look at new ways of engaging with the independent sector could secure additional funding for local housing solutions.

#### 16.4 *Local Services for Local People*

16.4.1 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 in placements away from their home. This is something we want to stop unless the person chooses it. For several years the number of people being placed away from home has been increasing – but it looks as though this has begun to turn around.

16.4.2 The VPST has been supporting a ‘local services for local people’ programme, which includes:

- an ‘action learning’ project in each of the nine regions that is bringing people back home, with the outcomes being shared regionally and nationally;
- targeted work with commissioners in several localities;
- a provider development programme and support to develop new, small scale providers to provide flexible support to people who challenge services;
- best practice from all this work being written up as guidance.

16.4.3 There is also a slow but steady growth in people being placed in private hospitals a long way away from home. If people are receiving active assessment and treatment this may be appropriate, but many are not. Also, people are sometimes placed away from home because they are labelled ‘challenging’ and commissioners have not developed local services with the skills to support them.

16.4.3 The policy to close long stay hospitals and NHS campuses is based on evidence that local community services provide better outcomes for people than institutional services. PCTs and local authorities should not be buying services in the private and independent sector that are similar in nature to hospitals and campuses. **The only reason a person with a learning disability should be an in-patient in an NHS or private sector hospital bed is because they are receiving an active programme of assessment or treatment with a view to moving back home to their local community.**

16.4.4 Maintaining momentum on the early signs of a reduction in out of area placements is a national and local task. To help with this:

- the ‘Mansell’ report on commissioning and providing services to people who challenge has been re-launched. The *Valuing People* delivery programme will provide support to help deliver this;

- *Valuing People* regional advisors will continue with the ‘local services for local people’ programme with data collected to assess progress;
- Discussions will be held with CSCI and the Healthcare Commission about how the numbers of people placed out of district can become a more influential determinant of good performance.

## 16.5 Action Summary

### 16.5.1 Nationally:

- commissioning and funding for learning disability ‘social care’ services will be moved from the NHS to local government;
- support for work to further understand changes in demand for learning disability services, prior to the next CSR;
- a national tool-kit for fair pricing of services to be launched in 2008;
- delivery support around the Mansell report and ‘local services for local people’.

### 16.5.2 Locally:

- local agreement to be reached on NHS resources to be transferred to local government;
- the development of effective multi-agency registers to inform forward planning;
- service co-ordinators and other lead professionals have a key role to play in bringing services together to meet the needs of this group;
- no purchasing of NHS or independent sector inpatient beds other than for active assessment and treatment.

## 16.6 The Vision for Three Years From Now

This will be different.....	We will know this because .....
Fully integrated local authority led commissioning of learning disability services will be taking place	Resources for ‘social care’ will be held by local authorities
Investment in learning disability services will reflect changing patterns of demand	There will be accurate ways, locally and nationally, of collecting data on population, demand and spend
There is a significant reduction in the numbers of people placed to live outside their local area.	Nationally collected and analysed data will confirm this

## 17 Getting Better at Checking How We Are Doing

### The Big Headlines

- Two new cross-government performance indicators on employment and housing
- A review of the NHS and adult social care performance framework in order to improve how we monitor learning disability service.
- Local learning disability partnerships to establish their own outcome indicators and report on progress with them in public

#### 17.1 Where Are We Now

17.1.1 Some of the current systems that collect information or check on progress have given us important information. For example, CSCI collected data tells us about increased expenditure on advocacy and more people taking up direct payments. The inspection systems of regulators help to identify poor performance. CSCI has been developing innovative ways of working such as employing ‘experts by experience’ – people with learning disabilities who are equal members of inspection teams, and developing accessible materials to help people living in residential care understand what is happening when inspections take place. The Healthcare Commission audit (see section 7) is helping both commissioners and providers get to grips with service problems.

17.1.2 However, there are clear weaknesses in the current performance, inspection and data collection systems for learning disabilities. For example, they failed to pick up on the poor performance and abuse in Cornwall. As a result, Ministers undertook to work with the regulators to review the performance framework and improve how we monitor learning disability services. Currently, the NHS does not report any information about the health of people with learning disabilities and not all social care data is relevant to modern learning disability services. Most data collected by the employment, education and housing sectors does not specifically report on people with learning disabilities – it uses wider definitions of disability which makes it difficult to get a picture of progress with *Valuing People*.

#### 17.2 The Next Steps

17.2.1 The performance and regulation system for learning disabilities needs to provide information and encouragement that supports *Valuing People Now*’s social inclusion and choice and control agenda.

17.2.2 Joint strategic needs assessments (see section 16) will require local agencies to collect and analyse information about the lives of people with learning disabilities. The Disability Equality Duty requires public bodies to check the impact of their policies on the lives of learning disabled people – especially where the outcomes for people with learning disabilities are worse than the population as a whole (e.g. health, employment, housing)

17.2.3 For the NHS and adult social services, action will be taken as promised by Ministers to review the performance framework in order to improve how we monitor learning disability services.

- 17.2.4 The ODI has consulted on a set of outcome-based indicators to monitor progress towards equality for disabled people until 2025. These proposals will be published shortly and the initial set of outcome-based indicators from across government will be published in the forthcoming ODI annual report 2007. These measures are a starting point in measuring progress towards disability equality, and do not cover all areas that disabled people have told us are important to measure. The ODI will work with partners across government and with disabled people to fill the gaps in available information.
- 17.2.5 Two new cross-government performance indicators will be introduced from 2008 to provide information on the social inclusion of people with learning disabilities. These will cover (i) the proportion of people with learning disabilities in real jobs and (ii) the accommodation status of people with learning disabilities and whether they have control over their housing situation. These indicators can then be used by local authorities and their partners as they identify priorities to be tackled through targets as part of local area agreements.
- 17.2.6 Local data collection outside the formal performance framework is essential and Local learning disability partnerships have an important role in coordinating this. Reviewing inter-agency data on people's lives and the services that support them, publicly setting local objectives and outcomes and then reporting on progress will greatly help delivery of *Valuing People Now*.
- 17.2.7 People with learning disabilities and families should be central to local and national inspections and service reviews. Both CSCI and the Healthcare Commission have set good examples on including people when doing this.
- 17.2.8 *Valuing People* commissioned a major survey of the lives of people with learning disabilities.<sup>24</sup> It was always intended that this would be repeated in the future to check progress. The DH is hoping to re-commission the survey in 2009.
- 17.2.9 The lack of centrally collected information about the lives of people with learning disabilities is a problem. The DH will therefore explore the potential to establish a 'learning disabilities observatory', similar to those for some other client groups, that regularly receives, analyses and reports on data about the lives of people with learning disabilities.

### 17.3 Action Summary

- 17.3.1 Nationally;
- work completed in relation to the commitment to strengthen the performance frameworks and data collection;
  - two new 'social inclusion' performance indicators introduced;
  - DH to progress the commissioning of a repeat survey of people's lives and the potential for establishing an 'observatory'.

---

<sup>24</sup> 'Survey of adults with learning difficulties in England 2003/2004,' September 2005, BMRB Ltd: [http://www.dh.gov.uk/en/Publicationsandstatistics/PublishedSurvey/ListOfSurveySince1990/Generalsurveys/DH\\_4081207](http://www.dh.gov.uk/en/Publicationsandstatistics/PublishedSurvey/ListOfSurveySince1990/Generalsurveys/DH_4081207)



### 17.3.2 Locally:

- joint strategic needs assessments, in compliance with the DED, should include accurate information about the lives of people with learning disabilities;
- local learning disability partnerships should voluntarily set local objectives based on *Valuing People Now* and measure and report on them (as at 15.3.2);
- consideration should be given to establishing targets in local area agreements based on the new social inclusion performance indicators.

### 17.4 *The Vision for Three Years From Now*

This will be different.....	We will know this because .....
All public bodies will have accurate information about the lives of people with learning disabilities	Joint strategic needs assessments will contain this information in compliance with the DED
The NHS will be reporting on the health of people with learning disabilities	To be decided as part of the review of the NHS performance framework
There will be a focus on jobs and housing for people	The socially excluded adults PSA will be reporting on this and these items will appear in the local government performance framework against which local authorities will report
Local cross-agency targets and objectives are voluntarily set and monitored in relation to delivering <i>Valuing People Now</i>	Local learning disability partnerships will be taking this forward and reporting on progress

## **The Consultation Process**

### **What Do You Think About *Valuing People Now*?**

We would like to know what you think about the things we have written in *Valuing People Now: From Progress to Transformation*.. There are three months for you to do this until 11 March 2008. After that, we will read what everyone has said and change things where it seems that we did not get them right. A final *Valuing People Now* will then be published in the spring.

We are interested in the views of as wide a range of people as possible – people with learning disabilities, families, carers, people who work with/for or in the services used by people with learning disabilities.

To help you let us know what you think, and to help us analyse what you say, we are asking people to provide answers on this form. You can send it to us at the address below or you can complete and submit a copy on-line at:

<http://www.dh.gov.uk/en/Policyandguidance/SocialCare/Deliveringadulthoodsocialcare/Learningdisabilities/index.htm>

You can also download copies of the questionnaire from the *Valuing People* Support Team website at [www.valuingpeople.gov.uk](http://www.valuingpeople.gov.uk) or from the Department of Health website on:

<http://www.dh.gov.uk/en/Policyandguidance/SocialCare/Deliveringadulthoodsocialcare/Learningdisabilities/index.htm>

### **About You**

[If the comments are from a group of people, and the group is mixed, please write in below how many people from each of the types of people listed were involved in producing the response.]

Are these comments from:

One person

☐

A group of people

☐

If a group, how many people were involved in producing this response

Are you (or the group of people): (please only mark one)

Self-advocates (people with a learning disability) ☐

Family Carers ☐

Healthcare professional working with people with a learning disability ☐

Social care professional working with people with a learning disability ☐

Managers or commissioners ☐

Other – please say what \_\_\_\_\_

### **What is your ethnic group?**

Choose ONE section from A to E, then tick the appropriate box to indicate your cultural background.

#### **A White**

British ☐

Irish ☐

Any other White background, please write in

#### **B Mixed**

White and Black Caribbean ☐

White and Black African ☐

White and Asian ☐

Any other Mixed background please write in:

**C Asian or Asian British**

Indian

☐

Pakistani

☐

Bangladeshi

☐

Any other Asian background, please write in:

**D Black or Black British**

Caribbean

☐

African

☐

Any other Black background, please write in:

**E Chinese or other Ethnic group**

Chinese

☐

Any other, please write in:

Please state the type of impairment that applies to you. People may experience more than one type of impairment, in which case you may indicate more than one. If none of the categories apply, please mark 'Other' and specify the type of impairment:

- Physical impairment, such as difficulty using your arms or mobility issues which means using a wheelchair or crutches
- Sensory impairment, such as being blind / having a serious visual impairment or being deaf / having a serious hearing impairment
- Mental health condition, such as depression or schizophrenia
- Learning disability / difficulty
- Autistic Spectrum Disorder
- Long-standing illness or health condition such as cancer, HIV, diabetes, chronic heart disease, or epilepsy
- Other (please specify)

It would help us if you put your name and where you are from. If this is a group response, then this is particularly important.

Name of individual or Group

---

Town or City or County

---

## The Big Priorities

Do you agree that we should identify a small number of priorities and give them more attention?

Yes

☐

No

☐

Do you think that the priorities we have identified are the right ones?

Personalisation (choice and control)

Yes

☐

No

☐

What people do with their days (including work)

Yes

☐

No

☐

Better health

Yes

☐

No

☐

More Choice about housing

Yes

☐

No

☐

Making *Valuing People* Happen

Yes

☐

No

☐

Any other topics you think should also be one of the Big Priorities?

Other comments about the Big Priorities?

---

**Please tell us what you think about the different sections on  
*Valuing People Now***

We would like you to tell us whether you think they have identified the right issues and actions, whether you disagree with anything, or whether we have missed out important things. Please mark the boxes, then put any comments at the end.

<b>Section</b>	<b>About Right</b>	<b>Missing Something</b>	<b>Has Things I Disagree With</b>
<b>Personalisation</b>			
<b>What people do during the day</b>			
<b>Better Health</b>			
<b>Improving People's Housing Situations</b>			
<b>Advocacy and rights</b>			
<b>Partnership with Families</b>			
<b>Including Everyone</b>			
<b>People as Local Citizens</b>			
<b>Transition</b>			
<b>Improving the Workforce</b>			
<b>National and Local leadership</b>			
<b>Better commissioning</b>			
<b>Checking How We Are Doing</b>			

**Comments:**

## Comments cont.

---

**There are some questions where we are particularly interested in knowing what you think. Please answer the following questions:**

Do you agree that a major focus on supporting people into paid work should be at the centre of planning day service changes?

Yes

☐

No

☐

Comments:



Do you agree that people should be offered regular comprehensive health checks?

Yes

☐

No

☐

Comments:

---

Do you agree about the increased focus on people having assured tenancies and owning their own homes?

Yes

☐

No

☐

Comments:

---

Do you agree that Partnership Boards should continue – but helped to be more effective?

Yes

☐

No

☐

Comments:

---

Do you agree with funding and commissioning of learning disability services (apart from what is clearly healthcare) moving from the NHS to local government?

Yes

☐

No

☐

Comments:

**Overall:**

Do you think that *Valuing People Now* has identified the most important issues for the next three years?

Definitely

☐

Yes – on the whole

☐

In some ways – but some important things are missed

☐

No – it has got many things wrong

☐

Comments:

---

Do you think the actions proposed in *Valuing People Now* will help change things:

A lot

☐

A bit

☐

Not at all

☐

What other actions would you like to see in *Valuing People Now*?

---

Please return your completed response form to:

Post: *Valuing People* Now Consultation  
Rm 120  
Department of Health  
Wellington House  
133 – 155 Waterloo Rd  
London  
SE1 8UG

Email: [valuingpeoplenow@dh.gsi.gov.uk](mailto:valuingpeoplenow@dh.gsi.gov.uk)