



Valuing People Now

*From progress to
transformation*

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Valuing People Now

From progress to transformation

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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 that 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 Department for Business, Enterprise and Regulatory Reform website at:

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

Responding to the consultation

For details of how to give us your views on *Valuing People Now*, please see page 107 of this document or go to:

www.dh.gov.uk/en/Consultations/Liveconsultations/DH_081014

Or, if you have questions about *Valuing People Now*, please e-mail valuingpeoplenow@dh.gsi.gov.uk

Comments on the consultation process itself

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

Consultations Co-ordinator
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, among 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 30 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 professionals 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 the areas in which 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.

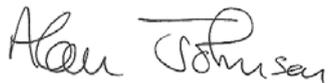
I know that there are many committed staff, carers and self-advocates who are determined, and rightly so, not to rest until we have achieved independent living for the vast majority, if not all people with learning disabilities. That is why the Government is determined to reinvigorate the agenda.

Valuing People Now: From progress to transformation sets out the priorities for the provision of services for people with learning disabilities over the years 2008–11. 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 focused 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 everyday experience of people with learning disabilities and their families.

A handwritten signature in black ink that reads "Alan Johnson". The signature is written in a cursive style with a large initial 'A'.

Rt Hon Alan Johnson MP
Secretary of State for Health

Part one: Executive summary and introduction

1 Executive summary

1.1 Overview

- 1.1.1 *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.
- 1.1.2 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.
- 1.1.3 *Valuing People Now* does not cover children with learning disabilities because other policies (including *Aiming High For Disabled Children*) are already taking new action forward for children.

1.1.4 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.

1.1.5 The main priorities for 2008 to 2011 are:

- **personalisation** – so that people have 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; and
- **making sure that change happens** and the policy is delivered – including making partnership boards more effective.

1.1.6 Sections 1.2 and 1.3 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; and

- checking that lives are improving for some of the most excluded people, for example people with complex disabilities and those from minority ethnic communities.

1.2 Big priorities

Personalisation

1.2.1 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; and
- work continuing to help more people have direct payments.

What people do during the day

1.2.2 Joined-up working between adult social services and 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 service 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; and
- government prioritisation of employment through the socially excluded adults PSA.

Better health

- 1.2.3 Several recent reports have raised concerns of how people with learning disabilities access healthcare. Actions to address this will include:
- initiatives to ensure that the NHS meets its legal obligations in relation to human rights and disability discrimination;
 - a new primary care service framework to support primary care trusts (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 (DH) 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 Commission's audit of NHS and private sector services; and
 - clear statements in the forthcoming NHS operating framework about delivery in relation to learning disability.

Improving people's housing situation

- 1.2.4 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 (CLG) and DH 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;
 - additional funding to support the closure of NHS campuses;
 - government employment of housing through the socially excluded adults PSA; and
 - support providers focusing on the social inclusion agenda described in *Valuing People Now*.

1.3 The wider agenda

Advocacy and rights

- 1.3.1 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 are 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*; and
 - 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

- 1.3.2 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 that the voice of carers is heard by government;
 - updating and extending the Prime Minister's strategy for 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; and
 - support for developing family leadership as part of the *Valuing People* delivery programme.

Including everyone

- 1.3.3 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 that people do not fall between different local services; and
 - a programme of work to improve the skills of the criminal justice system in working with people with learning disabilities.

People as local citizens

- 1.3.4 People want to be full members of 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 DH;
 - the Department for Transport working with the *Valuing People* delivery programme to ensure that transport initiatives are inclusive of people with learning disabilities. Local learning disability partnerships will get involved with the development of local transport plans so that this happens at a local level;
 - a focus on relationships when planning with people about their own lives, including personal and sexual relationships; and
 - support for parents with learning disabilities and their children as described in the existing good practice guidance, and the inclusion of parents with learning disabilities in new parenting initiatives supported by the Department for Children, Schools and Families (DCSF).

Transition to adulthood

- 1.3.5 As young people with learning disabilities 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; and
 - a focus on young people in transition for all aspects of *Valuing People Now*, that is jobs, housing, individual budgets etc.

Improving the workforce

1.3.6 New ways of working for staff who support people with learning disabilities 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; and
- local training to ensure a focus on skills to support choice, control and social inclusion.

1.4 The major priority – making it happen

1.4.1 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 that 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

1.4.2 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; and
- 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

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

- transferring funding for learning disability social care services from the NHS to local government. This means that local authorities, which are the lead commissioning authorities 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 number 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; and
- reissuing the Mansell report on people who challenge services, with a support programme to help its implementation.

Getting better at checking how we are doing

1.4.4 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); and
- encouraging local learning disability partnerships to establish their own outcome indicators and publicly report on progress against them.

2 Introduction

2.1 In 2001, the Government published *Valuing People: A New Strategy for Learning Disability for the 21st Century*. It was the first major government policy statement about learning disabilities for 30 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.

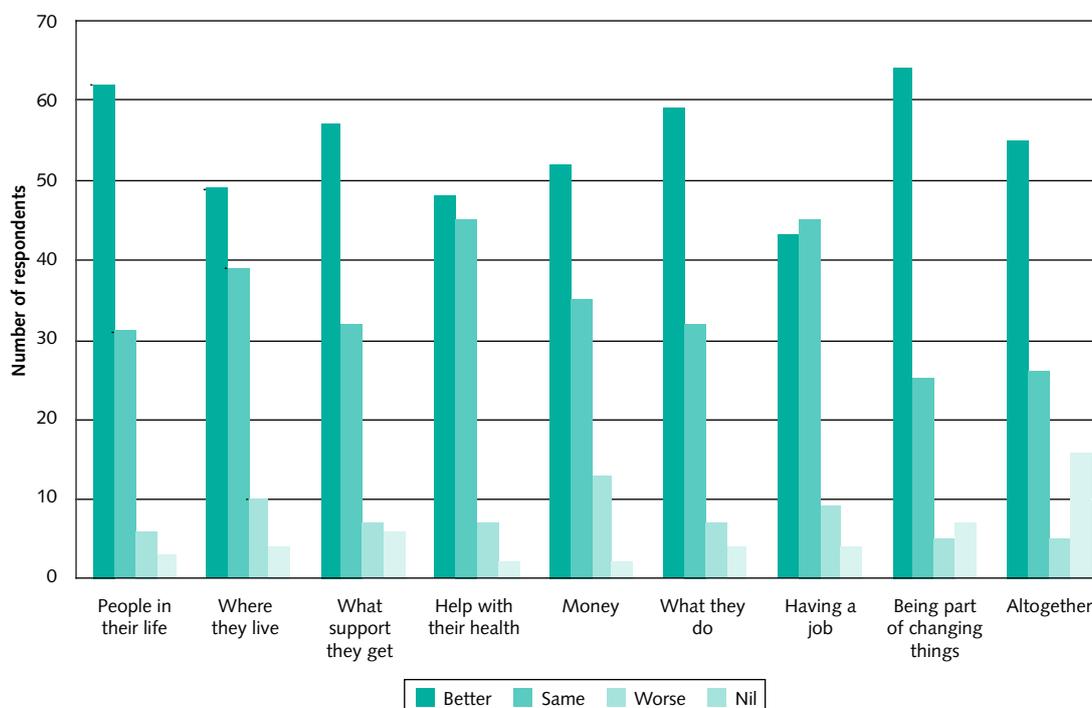
2.2 *Valuing People* was widely welcomed by people with learning disabilities, their families and people working in the learning disability field. Many said it was a groundbreaking policy because it stressed how people with learning disabilities are, above all else, people and citizens. It said that 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.

2.3 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 the way 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; and

- by amending the Disability Discrimination Act (DDA) 1995 in 2004 and 2005, rights for disabled people have been substantially improved and extended – for example, in relation to employment.
- 2.4 In addition, the Human Rights Act 1998 has influenced the policies and principles of *Valuing People*.
- 2.5 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.
- 2.6 In 2005, around 3,000 people contributed to the National Director's review of *Valuing People – The Story So Far*. This described good progress in some areas, including:
- people are being listened to more – both about their individual lives and in service planning;
 - person-centred planning, done properly, is making a difference to people's lives;
 - the Supporting People programme, which has helped many people to live independently;
 - direct payments are helping to change people's lives; and
 - organisations are working together better at a local level.
- 2.7 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* was published. However, in some areas (for example 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.

Figure 1: *The Story So Far* consultation¹



2.8 A short summary of progress so far with *Valuing People* is:

- there has been 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; and
- where change has happened, some people now feel it is getting difficult to move on to the next stage of change.

¹ *The Story So Far* consultation pack was aimed at advocacy groups. It asked groups to tell us whether life had got better in the last five years for the person they chose as part of the exercise in the pack.

- 2.9 The 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 to do 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.
- 2.10 *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 for Disability Issues (ODI).
- 2.11 *Valuing People Now* does not repeat all the evidence and arguments behind why the policy says what it does. These can be found in *The Story So Far, Our Health, Our Care, Our Say, Improving the Life Chances of Disabled People* and *Valuing People* itself.² *Valuing People Now* is concerned with describing the action that is required in order to make good on existing policy commitments.
- 2.12 We would welcome your comments on what *Valuing People Now* says by 28 March 2008. Details of how to comment are given on page 107. A final document will then be produced by summer 2008.

2 *Valuing People: The Story So Far... A New Strategy for Learning Disability for the 21st Century*, 2005, Valuing People Support Team, www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4107054
Our Health, Our Care, Our Say, 2006, Department of Health, www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4127453
Improving the Life Chances of Disabled People, 2005, Cabinet Office, www.cabinetoffice.gov.uk/upload/assets/www.cabinetoffice.gov.uk/strategy/disability.pdf

3 Children with a learning disability

- 3.1 *Valuing People* covered policy about children with learning disabilities as well as adults. Shortly afterwards, the Government produced several other policies about children which became the focus of change for children with learning disabilities. 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 section 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 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 special educational needs (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 number of children with SEN 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 that families are assigned 'key workers' to help them negotiate access to services.

- 3.5 The 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 £280 million for increasing short breaks/respite care for disabled children, £35 million for a childcare accessibility project to improve access to childcare for disabled children, and £5 million 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 they are needed;
- be clear about priorities for the next three years; and
- 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); and
- 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 2008–11 are:
- **personalisation** – 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, that is home ownership and real tenancies; and
 - **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, such as 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 decisions 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: Personal Social Services Research Unit).

| Year | Number of people with learning disabilities in receipt of a direct payment |
|---------|----------------------------------------------------------------------------|
| 2000/01 | 250 |
| 2001/02 | 480 |
| 2002/03 | 880 |
| 2003/04 | 1,840 |
| 2004/05 | 3,385 |
| 2005/06 | 5,485 |

- 5.1.2 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.³
- 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, the 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 planning⁴ 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 Team has worked with the Commission for Social Care Inspection (CSCI) in developing and starting to pilot tools so that their inspectors can make checking on person-centred planning an important part of their work. DH and DCSF 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

3 *A report on In Control's first phase 2003–2005*, 2006, In Control, www.library.nhs.uk/learningdisabilities/ViewResource.aspx?resID=187216

4 *The Impact of Person Centred Planning*, 2005, J. Robertson, E. Emerson, C. Hatton et al, Institute for Health Research, Lancaster University, www.lancs.ac.uk/fass/ihr/publications/ericemerson/the_impact_of_person_centred_planning_final_report.pdf

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; and
- 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 that 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; and
- 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. DH is working with key stakeholders (including the Association of Directors of Adult Social Services, Local Government Association and Improvement and Development Agency) 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 DH 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; and
- 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; and
- local partners should review and develop local person-centred planning strategies and prioritise 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 (DWP) to work with other government departments and key stakeholders, including employers and providers, to increase access to real, paid jobs for people with learning disabilities.
- DWP 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 2 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 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-centred 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; and

- forward planning. Good person-centred 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 that 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, and 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 Jobcentre Plus 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 retirement age and may want things other than work; and
- establish a local outcome (for example within three years) that no day centre should be segregated. Only invest in integrated facilities and have a decommissioning 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 ODI, DH, DWP, DCSF 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:

- SEN transition planning;
- post-16 education planning and provision;
- disability employment advice and support; and
- 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 order 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 DWP 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 learning disabilities;
- making sure the benefits system helps people into work; and
- 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 methods 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; and
- producing and sharing best practice advice in the employment of people with learning disabilities.

6.2.10 DWP 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 20 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; and
- 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 (DfES), DH and DWP 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 that the curriculum followed by learners is high quality, can be accredited and provide positive outcomes; and
 - improving the clarity and flexibility of funding to support learning and place the individual at the centre of planning services.

A detailed delivery plan is due to be published.

- 6.2.14 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

- 6.2.15 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 which addresses how all people and organisations can develop the attitudes and skills to involve people with learning disabilities. It will also need to consider physical resources – for example having public toilets in town centres with adult changing facilities so that 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 DWP, to achieve an increase in the number of people moving into real, paid jobs;
- consultation on the redesign of DWP employment services for disabled people that will actively seek and respond to the views of people with learning disabilities;
- the DWP and DH-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; and
- government departments will review their own employment of people with learning disabilities 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.

- reinvestment strategies should move from traditional day services to a social inclusion strategy; and
- public sector organisations to review and increase their employment levels of people with learning disabilities.

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 Service Agreement (PSA) indicator will collect this information. |
| Government itself will be employing more people with learning disabilities 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. |

7 Better health

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.
- Strategic health authorities (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.⁵

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

⁵ *Equal Treatment: Closing the Gap*, 2006, Disability Rights Commission, www.equalityhumanrights.com/en/publicationsandresources/Disability/Pages/Formalinvestigations.aspx
Treat Me Right!: Better health for people with a learning disability, 2004, Mencap, www.mencap.org.uk/download/treat_right.pdf
Death by Indifference, 2007, Mencap, www.mencap.org.uk/html/campaigns/deathbyindifference/reports.asp

with learning disabilities to understand the wider NHS issues. Work is under way to implement recommendations made from the Disability Rights Commission (DRC) formal investigation.

- 7.1.3 There has been a number of other national and local actions on health, for example:
- DH, working with NHS Primary Care Contracting, has developed and published a framework to support PCTs to commission primary care services for people with learning disabilities.⁶ 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*⁷ is a short leaflet of tips and advice about getting the best out of medical appointments. The easy read version of the leaflet was developed and tested with a range of groups including those with learning disabilities. These leaflets are being distributed to most GP surgeries and pharmacies in late 2007 and will 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.

6 *Primary Care Service Framework: Management of Health for People with Learning Disabilities in Primary Care*, 2007, NHS Primary Care Contracting, www.primarycarecontracting.nhs.uk/uploads/primary_care_service_frameworks/primary_care_service_framework__ld_v3_final.pdf

7 www.ldhealthnetwork.org.uk/questioninfo.pdf

7.1.5 Thus, there is 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, while also ensuring good quality, evidence-based specialist learning disability health services in all parts of the country.

7.2 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 that 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 that 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 DH 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; and
- a disability equality impact assessment of recent measures to increase patient choice.

Primary healthcare

- 7.2.3 In response to the DRC report, DH established a working group, with the DRC (which is now part of the Equality and Human Rights Commission), to take this work forward. The following actions are resulting from this:
- A framework for commissioning primary care for people with learning disabilities (see paragraph 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 services, providing individualised health action plans, and promoting better health outcomes and better involvement in healthcare for people with learning disabilities.
 - The development of GPs with a special interest in learning disability, who will be a useful resource for other GP practices in their area in improving the quality of services to people with learning disabilities.
 - DH 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 the 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, DH 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. DH 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 DH, 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 with and listening to local people. DH will ensure that PCTs include people with learning disabilities in this debate. Finally, DH 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 the 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; and
- 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.⁸ Good practice advice on the role of learning disability nursing has been recently issued by the Chief Nursing Officer.⁹
- 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 that 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 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 that form part of the wider government commitment to tackling social exclusion reflect

⁸ *Commissioning specialist adult learning disability health services*, 2007, Department of Health, www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_079987

⁹ *Good practice in learning disability nursing*, 2007, Department of Health, www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_081328

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 local authorities, through the local area agreement 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 local authorities (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 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* (NSF) 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 consider how 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 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 has been issued by the Chief Nursing Officer;
- future developments in mental health policy and delivery will fully include the mental health needs of people with learning disabilities;
- SHAs 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; and
- the operating framework will specifically address learning disability.

7.3.2 Locally:

- SHAs and PCTs should ensure that 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 learning disabilities; and
- 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... |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <p>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.</p> <p>The majority of people will have an identified health facilitator, health action plans and regular comprehensive health checks.</p> <p>PCTs will be actively engaged as full partners in the local multi-agency planning and review of learning disability services.</p> | <p>Local information on health service delivery will demonstrate equality of access in line with Disability Equality Duty requirements. There will be reduced usage of out-of-area placements.</p> <p>PCT commissioning plans, developed in partnership with local service users, will identify how local needs are being addressed and will inform local learning disability partnership reviews of progress.</p> <p>Local learning disability partnerships will report full and active participation from PCTs with up-to-date action for health frameworks.</p> |

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 learning disabilities 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 learning disabilities have a secure, long-term tenancy or own their own home – compared with 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 arrangement are coming to an end, in particular people living long term as an NHS inpatient. 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 that 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, £388.8 million 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 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 society expects for themselves. People with learning disabilities 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 number of people who live in their own homes or have assured tenancies in rented accommodation.** A new PSA 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, CLG and DH, 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 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; and

- 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 will include:

- building on best practice with housing registers and strategic needs assessment such as the London accessible housing register and assessment framework; and
- 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.¹⁰ 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 wants 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 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 HomeBuy scheme (that is, shared ownership); and
- Housing Corporation-funded investment in social housing. The Housing Corporation's prospectus encourages bids for housing for vulnerable people including people with learning disabilities.

¹⁰ www.rmd.communities.gov.uk/project.asp?intProjectID=12271

- 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 1990,¹¹ 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. DH recently announced a £175 million capital fund to help develop replacement housing and will work with the Housing Corporation to promote bidding for joint 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 departments. 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. The 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; and

11 *Caring for People: Community Care in the Next Decade and Beyond*, 1990, Department of Health.

- 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 that 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); and
- provide services and support that responds to people's different cultural backgrounds (section 11).

8.2.12 The Supporting People strategy,¹² 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 will proceed;
- housing is 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; and
- £175 million of capital funding and a grant to local authorities will support revenue costs, to enable the closure of NHS campuses.

8.3.2 Locally:

- the number of people receiving individual budgets and direct payments will increase, improving their choice and control over their housing situation;
- local authority care managers should have an increased focus on home ownership and assured tenancies as models for housing and support;
- local authority care managers will use person-centred planning with adults still living with families, to understand whether that is the people's preferred option and instigate plans accordingly;

¹² *Independence and Opportunity: Our Strategy for Supporting People*, 2007, Communities and Local Government, www.spkweb.org.uk/NR/rdonlyres/4E92E1E2-B5EF-42B4-ADOC-FE5B68C4330B/12855/bm07024supportingpeoplestrategy.pdf

- all NHS campuses should 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; and
- 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 live 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 about 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-advocacy leaders.
- Every locality should have user-led organisations in line with the recommendation in the Life Chances strategy.¹³

9.1 Where are we now?

9.1.1 *Valuing People* made the commitment to include people with learning disabilities in all policy about their lives ('nothing about us without us'). Since 2001, advocacy organisations have grown – the average spend by councils on learning disability advocacy in 2006/07 was £106,000 compared with £74,000 in 2003/04. People with learning disabilities tell us that they are listened to and involved more in decision making about their lives. Self-advocacy leadership has been growing, in part through the National Forum for People with Learning Disabilities. Over 60 national and regional self-advocacy 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.

¹³ *Improving the Life Chances of Disabled People.*

- 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 LINKs. 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 required capacity 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; and
 - 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 for 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 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; and
 - 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-advocacy 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 organisation in line with the recommendation in the Life Chances strategy – with full involvement of people with learning disabilities. DH 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 2009.¹⁴

14 www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_079734

- 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. The 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 on 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 to improve understanding of the Disability Equality Duty and consider which areas of local services are falling behind in providing equal outcomes and thus need targeted action in line with Disability Equality Duty 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. The 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 will be implemented to help improve the impact of advocacy; and
- around 10 action and learning sites between February 2008 and March 2009 will 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; and
- all partnership boards should focus on the Disability Equality Duty and areas for related action.

9.4 The vision for three years from now

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

10 Partnership with families

The big headlines

- A Standing Commission on carers to ensure that the voice of carers is heard by the Government.
- Updating and extending *Caring About Carers*, 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 for 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 £25 million per year increase in the carers grant; and
- 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 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;
- £3 million 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 among those identified as being a focus for this service; and

- £5 million 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 carer's 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; and
- ensuring that 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; and
- a support programme for family carer leadership.

10.3.2 Locally:

- as the Expert Carers programme is rolled out, local training should be made accessible; and
- actions as outlined in paragraph 10.2.5 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 will 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 the Government on whether things are improving. |
| Good quality short-term breaks and emergency support for families are more widely available. | Family carers and their organisations will 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 will 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 Carers programme. | Family carers and their organisations will 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; and
- people in prison.

Valuing People will only be successful when those at the greatest risk of exclusion have benefited 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', for example reliant on assisted ventilation or 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.¹⁵ 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.¹⁶ 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 2004/05. Some 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. Some 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).

¹⁵ *Death by Indifference*, 2007, Mencap, www.mencap.org.uk/html/campaigns/deathbyindifference/reports.asp

¹⁶ *Reaching Out*, 2006, Mencap, www.mencap.org.uk/html/ethnicity/reaching_out.asp

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, *Better services for people with an autistic spectrum disorder*, was issued in November 2006.¹⁷

People who offend or who are in prison

- 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. DH intends to work with the prison service to ensure that these people have the necessary support.
- 11.1.9 DH 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 who are subject to the criminal justice system. The document has been produced in conjunction with the Ministry of Justice, the Home Office, DCSF 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 or the courts and those 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.

¹⁷ *Better services for people with an autistic spectrum disorder: A note clarifying Government policy and describing good practice*, 2006, Department of Health, www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_065242

11.2 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 individualised services for people who challenge, rather than grouping services based on people's label or diagnosis.¹⁸

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, for example dysphagia, postural care;

¹⁸ *Services for people with learning disability and challenging behaviour or mental health needs*, 2007, Department of Health, www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_080129

- people having a named health facilitator as part of their person-centred planning arrangements;
- support for family carers – with particular attention on short-term breaks and meeting their own health needs and training;
- robust local plans to make sure that the ‘basics’ are available to enable people to pursue a fulfilling life, for example transport, personal care facilities; and
- particular attention to housing strategies, for example use of the Disabled Facilities Grant.

11.2.3 CSCI has 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 whether progress has been made.

Ethnicity

11.2.4 All services must comply with the requirements of the Race Relations (Amendment) Act 2000 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 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 autistic spectrum disorders. The policy outlined in this document applies directly to 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, 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 and 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.¹⁹ 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 reoffending.

11.3 Action summary

- 11.3.1 Nationally:
- ethnicity will continue to be a central part of the national *Valuing People* delivery programme;

¹⁹ *Positive Practice: Positive Outcomes: A Handbook for Professionals in the Criminal Justice System working with Offenders with Learning Disabilities*, 2007, Care Services Improvement Partnership, www.kc.csip.org.uk/viewresource.php?action=viewdocument&doc=98519&grp=1

- DH will consider extending the appointment of its part-time adviser on autism, subject to funding;
- learning disability will be included in the delivery programme around prison health; and
- good practice guidance for commissioners of forensic services for people with learning disabilities is forthcoming.

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 the obligations in the Race Relations (Amendment) Act, including developing data about people from minority ethnic 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 disabilities, once it is produced; and
- PCTs should ensure that prison health initiatives are inclusive of prisoners with learning disabilities in line with disability equality legislation.

11.4 The vision for three years from now

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

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 (DfT) will work to ensure that transport initiatives are benefiting people with learning disabilities.
- A greater focus on supporting personal relationships by care managers and service providers.
- Parents with learning disabilities will benefit from wider government initiatives to support parents.

12.1 Hate crime

Where are we now?

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

12.1.2 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 that 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 learning disabilities, is one way of helping to address this; and
- making sure that 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. While adult protection might be appropriate, people have the same rights as every other citizen to justice through the criminal justice system.

Next steps

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

12.1.4 The Home Office, in partnership with DH, will produce guidance for the criminal justice system and local authorities addressing the issues identified above. The Home Office is also funding two voluntary sector initiatives:

- Learning Together is 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.
- The PIP pack, a pack designed by self-advocates to raise awareness of hate crime and personal safety, is being distributed.

Action summary

12.1.5 Nationally:

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

12.1.6 Locally:

- learning disability partnerships will work together with crime and disorder reduction partnerships, using 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.

The vision for three years from now

| This will be different... | We will know this because... |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <p>Hate crime against people with learning disabilities is being properly addressed in every local area.</p> <p>People feel confident reporting hate crime, believing action will be taken.</p> | <p>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.</p> <p>Self-advocacy organisations will tell us things are improving. The data collected tells us action against hate crime is being taken.</p> |

12.2 Transport

Where are we now?

- 12.2.1 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.²⁰
- 12.2.2 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.

²⁰ 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, 2006, D. Jolly, M. Priestley and B. Matthews, Centre for Disability Studies, www.leeds.ac.uk/disability-studies/archiveuk/jolly/DRC%20transport%20research%20report%20-%20August%202006%20final.pdf

- 12.2.3 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:
- 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 (National Vocational Qualification) programmes for drivers;
 - DfT and the Disabled Persons Transport Advisory Committee will produce guidance material for 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; and
 - DfT has produced best practice guidance for transport providers on the provision of information for disabled people, *Inclusive Mobility*.²¹
- 12.2.4 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 to access key services such as healthcare, education and jobs. Accessibility planning is required as part of producing local transport plans. 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.²²

Next steps

- 12.2.5 Locally, local learning disability partnerships' work on transport should be focused in part on influencing the local transport plan. Advice has been produced by the Valuing People Support Team 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;

²¹ *Inclusive Mobility*, Department for Transport, www.dft.gov.uk/transportforyou/access/tipws/inclusivemobility

²² www.dft.gov.uk/pgr/regional/ltp/guidance/fltp/accessibleformatsforlocaltra3655

- the issues and costs around having a supporter travelling with them; and
- the problem of safety and hate crime on transport (see section 12.1).

12.2.6 DfT will work with the *Valuing People* delivery programme to determine 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; and
- 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.

Action summary

12.2.7 Nationally:

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

12.2.8 Locally:

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

The vision for three years from now

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

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 with learning disabilities 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, which can 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; and
- 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 sex and relationship education;
- organising service provision in a way that helps people's social contacts, for example 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; and
- positively supporting same-sex relationships where that is the choice of people.

12.4 Parents with learning disabilities

Where are we now?

12.4.1 *Valuing People* highlighted the need for services to support parents with learning disabilities as did the Treasury/DfES Children and Young People Review²³ and the Social Exclusion Task Force.²⁴ This included a commitment that parents with learning disabilities and their children would benefit from all initiatives aimed at supporting parents and children.

23 *Aiming High for Disabled Children: Better Support for Families*, 2007, HM Treasury/Department for Education and Skills, www.hm-treasury.gov.uk/media/C/2/cyp_disabledchildren180507.pdf

24 www.cabinetoffice.gov.uk/upload/assets/www.cabinetoffice.gov.uk/social_exclusion_task_force/chronic_exclusion/psa_da_16.pdf

- 12.4.2 DH and DfES (now the DCSF) have jointly issued good practice guidance on working with parents with learning disabilities. The Social Care Institute for Excellence (SCIE) has carried out a knowledge review and developed a resource guide for joint working across children's and adults' services to support disabled parents.
- 12.4.3 There is clear evidence that there are increasing numbers of parents with learning disabilities 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 adult specialist services, while mainstream services sometimes struggle to meet their needs. Research evidence illustrates a need for independent advocacy.

Next steps

- 12.4.4 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.
- 12.4.5 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.
- 12.4.6 DCSF 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 schools and Sure Start children's centres. This will include an action research project – the Parenting Implementation Project – with families with parents with disabilities, including those with learning disabilities as part of the target group.

Action summary

12.4.7 Nationally:

- DH and DCSF will ensure that the information they publish aimed at parents is available in accessible formats; and
- the Care Services Improvement Partnership (CSIP) will work with relevant government departments and the Working Together Network to disseminate the existing good practice guidance, alongside the SCIE resource guide.

12.4.8 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; and
- inter-agency parenting support initiatives should be inclusive of parents with learning disabilities.

The vision for three years from now

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

13 Making the transition to adulthood a positive experience

The big headlines

- A £19 million 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* (such as jobs, housing, individual budgets).

13.1 Where are we now?

- 13.1.1 Families and young people still say that 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, that is, 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 NSF, the Person-Centred Transitions programme 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. Some 350 people have been trained to facilitate person-centred reviews with young people, while 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 that outcomes for people are beginning to change. The further education sector is now joining in. DH and DCSF will continue to support this initiative.

13.2 Next steps

- 13.2.1 We know about the problems with the transition process and we know what is needed to make things work. The challenge is to make that happen. The Government has recently announced new funding for

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 £19 million 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 the ages of 14 and 25.
- 13.2.3 DH 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 undertake comprehensive health checks.

13.3 Action summary

13.3.1 Nationally:

- the Person-Centred Transitions programme will be extended and expanded.

13.3.2 Locally:

- every local area should have a multi-agency transition strategy, led by a 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 programme should be the norm; and
- 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... |
|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------|
| <p>Every young person with a learning disability and with a statement of SEN will have person-centred reviews from the age of 14 to 19.</p> | <p>Young people will tell us that they are feeling more supported and have a real say about their future.</p> |
| <p>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.</p> | <p>Evaluation of the Transition Support Programme will tell us this is happening.</p> |
| <p>Young people will leave school and enter paid work and education in far greater numbers than at present.</p> | <p>The number of young people recorded as not in education, employment or training will show this reduction.</p> |
| <p>A substantial increase in the number of young people taking up individual budgets and direct payments.</p> | <p>Nationally collected and analysed data will tell us this.</p> |

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 (LDQ).
- Local training to ensure a focus on skills to support choice, control and social inclusion.

14.1 Where are we now?

- 14.1.1 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.
- 14.1.2 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; and
- Skills for Care taking responsibility for developing the Learning Disability Awards Framework (LDAF) 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 learning disabilities.

14.2 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 the LDQ – in particular beyond induction modules. Work will take place to ensure a continued focus on achieving the 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:

- DH 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; and
- Skills for Care will lead on the further development and take-up of the LDQ.

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; and
- 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... |
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| 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 LDQ. | 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 be demonstrably in line with the <i>Valuing People</i> agenda. | People using services will encounter staff with a greater understanding of learning disabilities. |

Part four: The major 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 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 for People with Learning Disabilities** has played an important role and has influenced government policy on important matters. By using the nine regional forums 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 that 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 Valuing People Support Team, there would have been much less progress.
- The **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; and
- continue to support the Task Force for a further three years. However, the title 'task force' does not reflect its role, which is to review progress on *Valuing People* and make recommendations to the Government on learning disability issues. Its title and membership will thus be reviewed with effect from April 2008.

- 15.2.3 A ministerially led, cross-government group, currently called the Learning Disability Programme Board, will meet regularly to report on progress on 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 for 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 DH 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 in 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, and most of it is then transferred to local authorities. Annual allocations are based on a regular census. The benefits of the OLS system (that is, 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, the 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; and
- 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 for their area. The local strategic partnership 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 Bill²⁵ 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 the 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 Valuing People Support Team 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 round, and meets every few weeks as a board to discuss and review its work, rather than just thinking about the partnership board as a meeting.

| Effective partnership boards... | Weak partnership boards... |
|--------------------------------------------------------------------------------|-------------------------------------------------------------------|
| Concentrate on developing partnerships all year round. | Hardly exist outside the 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 than the outcomes. |
| Are properly supported and resourced to do their job well. | Exist by people squeezing it around other responsibilities. |

²⁵ The Local Government and Public Involvement in Health Act 2007, www.opsi.gov.uk/acts/acts2007/pdf/ukpga_20070028_en.pdf

| Effective partnership boards... | Weak partnership boards... |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <p>Are co-chaired by a senior, elected executive member of the local authority and a person with a learning disability (and/or family carer).</p> | <p>Are chaired by a learning disability manager or someone at social services assistant director level or below.</p> |
| <p>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.</p> | <p>See people from mainstream services as problematic people who do not turn up to meetings.</p> |
| <p>Properly support and resource self-advocates and family carers to be influential members of the board.</p> | <p>Marginalise self-advocates and families in meetings.</p> |
| <p>Ensure that self-advocates, families and the voluntary sector are elected by wider constituencies and then supported to communicate back to the people they are representing.</p> | <p>Allow self-advocates, families and the voluntary sector to be selected or appointed by the local authority with no communication with wider groups or people.</p> |
| <p>Have meetings that are an event, with a range of techniques used to discuss and deal with issues.</p> | <p>Use traditional committee meeting structures.</p> |
| <p>Publicise accessible meetings and minutes.</p> | <p>Have private meetings and people do not know what is going on.</p> |
| <p>Set themselves clear objectives and publicly report on what they have achieved (including to the council overview and scrutiny committee and local strategic partnership).</p> | <p>Have no performance culture and never question their own effectiveness.</p> |

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 of *Valuing People*.

15.3 Action summary

15.3.1 Nationally:

- there will be continued funding and redesign of national support structures;
- the LDDF will be continued but with funding being paid directly to local authorities;
- the role of partnership boards will be further clarified in guidance in the spring;
- Valuing People regional advisers will prioritise supporting best practice reviews of all partnership boards in 2008;
- the Government will discuss with CSCI the potential for both targeted and general reviews of partnership board effectiveness; and
- a new *Valuing People Now* awareness strategy will be developed.

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 local strategic partnerships) on achievements and future plans; and
- 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... |
|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <p>Learning disability partnerships in all parts of the country will be effectively influencing decisions about the planning and delivery of public services.</p> <p>LDDF will be fully used across all the country in line with the National Indicator Set.</p> <p>Significant progress will have been made on all priority areas in <i>Valuing People Now</i>.</p> | <p>Partnership boards will tell us this and CSCI reviews will confirm it.</p> <p>Nationally collected and analysed data will confirm this.</p> <p>All the ways described elsewhere in this report will have confirmed it.</p> |

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 inpatient in an NHS or private sector hospital 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 who have) the availability of an appropriate range of support 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.

16.1.4 There are some particular issues for learning disability commissioning that need attention. This section considers the three issues of:

- commissioning responsibility;
- funding and resources; and
- 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* restated 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. It is likely 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 the Government, if possible in 2009/10, but based upon spend in 2007/08. Further detail on how this will be achieved will be announced shortly.

- 16.2.5 This change will provide greater certainty about resources 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, that is equal access to good quality healthcare.

16.3 Money and resources

- 16.3.1 Spending on social care for adults with learning disabilities (at 2005/06 prices excluding Supporting People) has increased from approximately £1.5 billion in 1995/96 to approximately £3 billion in 2005/06. 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 among some South Asian communities.
- 16.3.2 Added to this, people and their families now have higher expectations about their lives than 30 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. Paragraph 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 section 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 CSIP²⁶ also shows that those councils that commission more individualised services achieve better outcomes for people at no additional cost, compared with councils that purchase the greatest 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; and
- use of these tools, when developed, which will be important in the short to medium term – Our strategy is to decommission specialised regional services wherever possible with a direction towards housing

²⁶ *Commissioning for Adults with Learning Disabilities: A Tale of Two Nations*, 2007, CSIP, www.socialcare.csip.org.uk/_library/two_nations.pdf

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 which 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 Valuing People Support Team 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; and
 - 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 placements 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.
- 16.4.4 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 inpatient in an NHS or private sector hospital is because they are receiving an active programme of assessment or treatment with a view to moving back home to their local community.**

16.4.5 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 relaunched. The *Valuing People* delivery programme will provide support to help deliver this;
- Valuing People regional advisers will continue with the 'local services for local people' programme with data collected to assess progress; and
- discussions will be held with CSCI and the Healthcare Commission about how the number 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 will be undertaken, prior to the next CSR;
- a national toolkit for fair pricing of services will be launched in 2008; and
- delivery support around the Mansell report and 'local services for local people' will be provided.

16.5.2 Locally:

- agreement should be reached on NHS resources to be transferred to local government;
- the development of effective multi-agency registers should inform forward planning;
- service coordinators and other lead professionals have a key role to play in bringing services together to meet the needs of this group; and
- there should be 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 number 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 services.
- 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 to 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 Next steps

- 17.2.1 The performance and regulation system for learning disabilities needs to provide information and encouragement that supports the *Valuing People Now* 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 people with learning disabilities – especially where the outcomes for people with learning disabilities are worse than for the population as a whole (for example, 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 the 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.²⁷ It was always intended that this would be repeated in the future to check progress. DH is hoping to recommission the survey in 2009.
- 17.2.9 The lack of centrally collected information about the lives of people with learning disabilities is a problem. DH will therefore explore the potential to establish a 'learning disabilities observatory', similar to those for some other client groups, which regularly receives, analyses and reports on data about the lives of people with learning disabilities.

17.3 Action summary

- 17.3.1 Nationally:
- work will be completed in relation to the Written Ministerial Statement commitment to strengthen the performance frameworks and data collection;

²⁷ *Survey of adults with learning difficulties in England 2003/04, 2005*, BMRB Ltd, www.dh.gov.uk/en/Publicationsandstatistics/PublishedSurvey/ListOfSurveySince1990/Generalsurveys/DH_4081207

- two new social inclusion performance indicators will be introduced; and
- DH will progress the commissioning of a repeat survey of people's lives and explore the potential for establishing an 'observatory'.

17.3.2 Locally:

- joint strategic needs assessments, in compliance with the Disability Equality Duty, 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 paragraph 15.3.2); and
- 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 Disability Equality Duty. |
| 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. |

18 Consultation questions

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 28 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 – including people with learning disabilities, families, carers and 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 post or email it to us at the addresses below. You can download copies of the questionnaire from the Valuing People Support Team website at: www.valuingpeople.gov.uk or from the DH website at: www.dh.gov.uk/en/Consultations/Liveconsultations/DH_081014.

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 specify _____

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 specify: _____

B Mixed

- White and black Caribbean
- White and black African
- White and Asian
- Any other mixed background, please specify: _____

C Asian or Asian British

- Indian
- Pakistani
- Bangladeshi
- Any other Asian background, please specify: _____

D Black or black British

- Caribbean
- African
- Any other black background, please specify: _____

E Chinese or other ethnic group

- Chinese
- Any other ethnic group, please specify: _____

Disability

Please tick 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 tick '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 fill in 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 during the day (including work) Yes No

Better health Yes No

Improving people's housing situation Yes No

Making *Valuing People* happen Yes No

Are there any other topics that you think should also be one of the big priorities?

Do you have any other comments about the big priorities?

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

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

| Section | About right | Missing something | There are things I disagree with |
|---------------------------------------------|-------------|-------------------|----------------------------------|
| Personalisation | | | |
| What people do during the day | | | |
| Better health | | | |
| Improving people's housing situation | | | |
| Advocacy and rights | | | |
| Partnership with families | | | |
| Including everyone | | | |
| People as local citizens | | | |
| Transition to adulthood | | | |
| Improving the workforce | | | |
| Local and national leadership and support | | | |
| Better commissioning | | | |
| Getting better at checking how we are doing | | | |

Comments

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

Do you agree that supporting people into paid work should be a major focus and 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 that the funding and commissioning of learning disability services (apart from what is clearly healthcare) should move 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 that the actions proposed in *Valuing People Now* will help change things?

- Yes, a lot
- Yes, a bit
- No, not at all



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