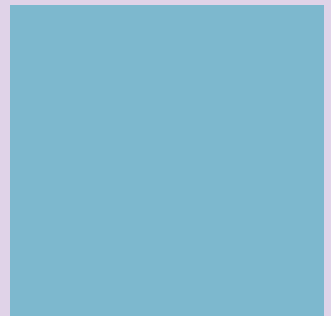
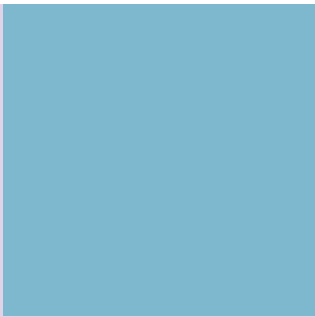


Valuing People Now

'Making it happen for everyone'

Impact Assessment Report



DH INFORMATION READER BOX

Policy HR/Workforce Management Planning Clinical	Estates Commissioning IM & T Finance Partnership Working
Document purpose	Policy
Gateway reference	10531
Title	Valuing People Now: a new three-year strategy for learning disabilities
Author	Department of Health
Publication date	19 January 2009
Target audience	PCT CEs, NHS Trust CEs, SHA CEs, Care Trust CEs, Foundation Trust CEs, Local Authority CEs, Directors of Adult SSs
Circulation list	Medical Directors, Directors of PH, Directors of Nursing, NHS Trust Board Chairs, Directors of HR, Directors of Finance, Allied Health Professionals, GPs, Directors of Children's SSs, Voluntary Organisations/NDPBs
Description	Valuing People Now sets out the Government's strategy for people with learning disabilities for the next three years following consultation. It also responds to the main recommendations in Healthcare for All, the Independent Inquiry into access to healthcare for people with learning disabilities
Cross reference	Valuing People (2001); Valuing People Now: The Delivery Plan: Making it happen for everyone (2009); Summary of responses to the consultation on Valuing People Now: From progress to transformation (2009)
Superseded documents	Valuing People Now: From Progress to Transformation (2007)
Action required	N/A
Timing	N/A
Contact details	Social Care Policy and Innovation Department of Health Room 116 Wellington House 133-155 Waterloo Road email: scpi-enquiries@dh.gsi.gov.uk www.Dh.gov.uk/en/Policyandguidance/Socialcare/Deliveringadultsocialcare/Learningdisabilities/index.htm
For recipient use	

Summary: Intervention & Options

Department /Agency: Department of Health	Title: Impact Assessment of Valuing People Now (VPN)	
Stage: final	Version: 1	Date: 9 January 2009
Related Publications: Valuing People (2001); Valuing People Now consultation (2007); Healthcare for All (July 2008)		

Available to view or download at:

<http://www.dh.gov.uk>

Contact for enquiries: **Pam Nixon**

Telephone: **020 7972 4901**

What is the problem under consideration? Why is government intervention necessary?

People with learning disabilities still do not have equality of access to, and quality of response from, local services and healthcare, nor do they have sufficient choice over where and how they live their lives. Valuing People issued in 2001 was intended to address these concerns, but recent reports, including Healthcare for All, have shown that progress is slow. As a result the Department is refreshing Valuing People based on a public consultation carried out in 2008. The Reports and the consultation have focussed efforts on providing better healthcare and ensuring more fulfilled lives.

What are the policy objectives and the intended effects?

The main policy objectives for people with learning disabilities are improving: access to healthcare; the quality of the NHS response to meeting their health needs; health outcomes and preventing early death; local planning by the provision of better data and information; the integration of care and other statutory services; people's inclusion in their communities and reduce marginalisation.

The policy objectives of VPN overlap with other policies, not the subject of this IA (the Carers Strategy and personalised services through transformation of social care.)

What policy options have been considered? Please justify any preferred option.

Talking to experts and stakeholders and following a public consultation, different measures have been considered. The most effective and practical are presented as recommendations within 2 options:

Option 1 - Do nothing and stop action already underway under option 2.

Option 2 - Implement recommendations 1,2,5,6,7,9 and 10 already underway under VPN.

Option 3 - Implement option 2 and add recommendations 3,4 and 8 (Public Health Observatory, Confidential Inquiry). Option 3 is the preferred option.

When will the policy be reviewed to establish the actual costs and benefits and the achievement of the desired effects? The policy sets the framework for the next 3 years, to be reviewed in 2011. The health check DES (Rec 6) will be evaluated at an early stage to assess value for money performance.

Ministerial Sign-off For final proposal/implementation stage Impact Assessments:

I have read the Impact Assessment and I am satisfied that (a) it represents a fair and reasonable view of the expected costs, benefits and impact of the policy, and (b) the benefits justify the costs.

Signed by the responsible Minister:



Date:

19.01.2009

Summary: Analysis & Evidence

Policy Option: 2	Description: Implement recommendations 1,2,5,6,7,9 and 10
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COSTS	ANNUAL COSTS		Description and scale of key monetised costs by ‘main affected groups’ The key components of the costs over 3 years (PV) are: health checks (£58.6m); liaison nurses (£15.9m); health facilitators (£14.5m) and health action plans (£10.9m). The key one-off costs (PV) are: health action plans (set up costs) (£5.9m); acute sector training (£5.6m) and DES training (£4.1m).
	One-off (Transition)	Yrs	
	£ 5.6m	3	
	Average Annual Cost (excluding one-off)		
£ 36.2m		Total Cost (PV) £ 120.6m	

Other key non-monetised costs by ‘main affected groups’ Non-quantified costs include additional burdens on health and social care due to better identification of need, greater take-up of services and increase in numbers of those who are known to services

BENEFITS	ANNUAL BENEFITS		Description and scale of key monetised benefits by ‘main affected groups’
	One-off	Yrs	
	£ not quantified	3	
	Average Annual Benefit (excluding one-off)		
£ not quantified		Total Benefit (PV) £ not quantified	

Other key non-monetised benefits by ‘main affected groups’ Non-quantified benefits include increase in the quality of healthcare experience for people with learning disabilities and their carers; greater awareness of healthcare professionals of their needs; increase in health screening and medical treatment; increased access to services and in quality of life.

Key Assumptions/Sensitivities/Risks Costs, benefits and funding for year 2 onwards subject to funding decisions. Assumptions are based on not everyone with learning disability accessing health action planning and health checks in years 1 and 2. See Annex C for list of assumptions.

Price Base	Time Period	Net Benefit Range (NPV) £ -241.3m to -74.3m	NET BENEFIT (NPV Best estimate) £ -120.6m
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What is the geographic coverage of the policy/option?	England				
On what date will the policy be implemented?	April 2009				
Which organisation(s) will enforce the policy?	PCTs, SHAs, LAs				
What is the total annual cost of enforcement for these organisations?	£				
Does enforcement comply with Hampton principles?	Yes				
Will implementation go beyond minimum EU requirements?	No				
What is the value of the proposed offsetting measure per year?	£				
What is the value of changes in greenhouse gas emissions?	£				
Will the proposal have a significant impact on competition?	No				
Annual cost (£-£) per organisation (excluding one-off)	<table style="width: 100%; text-align: center; border-collapse: collapse;"> <tr> <td style="width: 25%; padding: 2px;">Micro</td> <td style="width: 25%; padding: 2px;">Small</td> <td style="width: 25%; padding: 2px;">Medium</td> <td style="width: 25%; padding: 2px;">Large</td> </tr> </table>	Micro	Small	Medium	Large
Micro	Small	Medium	Large		
Are any of these organisations exempt?	<table style="width: 100%; text-align: center; border-collapse: collapse;"> <tr> <td style="width: 25%; padding: 2px;">No</td> <td style="width: 25%; padding: 2px;">No</td> <td style="width: 25%; padding: 2px;">N/A</td> <td style="width: 25%; padding: 2px;">N/A</td> </tr> </table>	No	No	N/A	N/A
No	No	N/A	N/A		

Impact on Admin Burdens Baseline (2005 Prices) (Increase - Decrease)

Increase	£	Decrease	£	Net Impact	£
Key: Annual costs and benefits: Constant Prices (Net) Present Value					

Summary: Analysis & Evidence

Policy Option: 3	Description: PREFERRED OPTION Implement all recommendations
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COSTS	ANNUAL COSTS		Description and scale of key monetised costs by 'main affected groups' The key components of the costs over 3 years (PV) are: health checks (£58.6m); liaison nurses (£15.9m); health facilitators (£14.5m) and health action plans (£10.9m). The key one-off costs (PV) are: health action plans (set up costs) (£5.9m); acute sector training (£5.6m); and confidential inquiry (£3.8m).
	One-off (Transition)	Yrs	
	£ 7.5m	3	
	Average Annual Cost (excluding one-off)		
£ 36.2m			Total Cost (PV) £ 126m

Other key non-monetised costs by 'main affected groups' Non-quantified costs include additional burdens on health and social care due to better identification of need, greater take-up of services and increase in numbers of those who are known to services

BENEFITS	ANNUAL BENEFITS		Description and scale of key monetised benefits by 'main affected groups'
	One-off	Yrs	
	£ not quantified	3	
	Average Annual Benefit (excluding one-off)		
£ not quantified			Total Benefit (PV) £ not quantified

Other key non-monetised benefits by 'main affected groups' Non-quantified benefits include increase in the quality of healthcare experience for people with learning disabilities and their carers; greater awareness of healthcare professionals of their needs; increase in health screening and medical treatment; increased access to services and in quality of life

Key Assumptions/Sensitivities/Risks Costs, benefits and funding for year 2 onwards subject to funding decisions. Assumptions are based on not everyone with learning disability accessing health action planning and health checks in years 1 and 2. See Annex C for list of assumptions

Price Base	Time Period	Net Benefit Range (NPV) £ -247.9m to -76.6m	NET BENEFIT (NPV Best estimate) £ -126m
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What is the geographic coverage of the policy/option?	England				
On what date will the policy be implemented?	April 2009				
Which organisation(s) will enforce the policy?	PCTs, SHAs, LAs				
What is the total annual cost of enforcement for these organisations?	£ nil				
Does enforcement comply with Hampton principles?	Yes				
Will implementation go beyond minimum EU requirements?	No				
What is the value of the proposed offsetting measure per year?	£				
What is the value of changes in greenhouse gas emissions?	£				
Will the proposal have a significant impact on competition?	No				
Annual cost (£-£) per organisation (excluding one-off)	<table style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 25%; text-align: center;">Micro</td> <td style="width: 25%; text-align: center;">Small</td> <td style="width: 25%; text-align: center;">Medium</td> <td style="width: 25%; text-align: center;">Large</td> </tr> </table>	Micro	Small	Medium	Large
Micro	Small	Medium	Large		
Are any of these organisations exempt?	<table style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 25%; text-align: center;">No</td> <td style="width: 25%; text-align: center;">No</td> <td style="width: 25%; text-align: center;">N/A</td> <td style="width: 25%; text-align: center;">N/A</td> </tr> </table>	No	No	N/A	N/A
No	No	N/A	N/A		

Impact on Admin Burdens Baseline (2005 Prices) (Increase - Decrease)

Increase	£	Decrease	£	Net Impact	£
Key: Annual costs and benefits: Constant Prices				(Net) Present Value	

Evidence Base (for summary sheets)

[Use this space (with a recommended maximum of 30 pages) to set out the evidence, analysis and detailed narrative from which you have generated your policy options or proposal. Ensure that the information is organised in such a way as to explain clearly the summary information on the preceding pages of this form.]

Introduction

1. In 2001 Valuing People set out the Government's strategy to address the health and social care needs of people with learning disabilities. Since then there has been considerable research, discussed later in this document, on the needs of people with learning disabilities and the extent to which these needs are being met by statutory and non-statutory services. There have also been a number of reports, also discussed later in this document, following complaints or incidents involving people with learning disabilities, which have raised concerns about the way services respond to their needs. As a result the Government decided to revisit Valuing People, including a public consultation undertaken between December 2007 and March 2008, to inform its new strategy, *Valuing People Now*. The most recent significant report, that of the Inquiry by Sir Jonathan Michael into healthcare for people with learning disabilities and published in July 2008¹, provided considerable support for many of the measures now being proposed.

Background

2. Valuing People² (2001) and research by Eric Emerson & Chris Hatton^{3 4} made estimates of the numbers of people with moderate to severe learning disabilities, who tend to be known to services, and of those with mild to moderate learning disabilities, who are less likely to be known to services. These estimates (in thousands) are shown in the table below.

ESTIMATED NUMBERS IN 000'S

	YEAR	REPORT/AUTHOR	UNDER 20 YRS	20-65 YRS	OVER 65 YRS
Moderate to Severe known to services	2001	Valuing People	65	120	25
	2004	Emerson and Hatton('04)	55	152	17
	2009	Emerson and Hatton('08)		201	
	2010	Emerson and Hatton('08)		214	
	2011	Emerson and Hatton('08)		226	
All people with learning disabilities	2001	Valuing People		806	
	2004	Emerson and Hatton('04)	190	795	127
	2011	Emerson and Hatton('04)		868	
	2021	Emerson and Hatton('04)		908	

3. Emerson and Hatton also estimated that the total number of adults with a learning disability would increase by 8% by 2011 and by 14% by 2021. Significantly, growth

¹ *Healthcare for All*, Report of the Independent Inquiry into Access to Healthcare for People with Learning Disabilities, Sir Jonathan Michael, DH, July 2008

² *Valuing People: A New strategy for Learning Disability for the 21st Century*, Department of Health Cm5086

³ Eric Emerson & Chris Hatton 'Estimating Future Need/Demand for Supports for Adults with Learning Disabilities in England' Institute for Health Research, Lancaster University (2004)

⁴ Eric Emerson and Chris Hatton *Estimating Future Need for Adult Social Care services for People with Learning Disabilities in England*, Centre for Disability Research (2008)

projection shows much higher increases in the number of adults aged over 60.⁵ It is also expected that there will be growth in the complexity of disabilities, due to improvements in maternal and neo natal care and improved general healthcare for adults which will lead to increased life expectancy.⁶

4. The more recent paper from the Centre for Disability Research, published in November 2008, looked at the numbers of people with learning disabilities using social care services. This estimated that the number of adults with learning disabilities known to services in 2006/7 was 187,000 whilst those using services was 137,000. The implication of the research is that more people with mild to moderate disabilities will become known to, and start using, services. Thus, the estimated number of people using social care services is set to increase by more than 50% by 2018, to 223,000, and nearly double by 2026.

5. *Our Health Our Care Our Say*⁷ set out local authorities' and health services' wider role in ensuring mainstream services are accessible, and that being inclusive is part of the general health and well-being of local communities.

Structure of this impact assessment

6. This document assesses the impact in cost and non-monetary terms of the actions arising from *Valuing People Now: A New Three-Year Strategy for people with learning disabilities*. Although *Valuing People Now* is a cross-government strategy, the impact assessment focuses on its impact on health and social care. Section I of the impact assessment covers 'Healthcare' (discussed in Chapter 3 of *Valuing People Now: Having a Life*). Section II considers measures to 'Support Delivery' through improving the capacity and capability to support delivery at a regional and local level and Section III considers 'Better Commissioning'. Both of these sections are discussed in Chapter 5 of *Valuing People Now: Making it Happen*. Annex B sets out the implications for other sections of *Valuing People Now* including references to impact assessments on individual policies.

Rationale for government intervention

7. The framework of legislation, including the Human Rights Act, the Disability Discrimination act and the Mental Capacity Act, supports universal, fair, equally accessible, effective and safe health and social care for all those entitled to receive it, including people with learning disabilities. Various reports, discussed above, including *Healthcare for All* have examined progress of Valuing People, the strategy set out in 2001 by the Government to address the health and other needs of people with learning disabilities. The evidence shows that Valuing People is working, but it is not working quickly enough, nor is it reaching everyone with learning disabilities.

8. The Government is therefore refreshing the policy to invigorate it and ensure it concentrates on those issues that really matter to people with learning disabilities and their carers. As part of the refresh, the Government carried out a public consultation in

⁵ Emerson E, Hatton C. op cit (2004)

⁶ Emerson E, Hatton C. op cit (2004)

⁷ *Our Health, Our Care, Our Say* White Paper 2006 (Department of Health)

2008, which attracted over 2,000 responses. The outcome of that⁸, together with the conclusions of a number of reports and inquiries, has provided a more focussed approach on a number of issues, as follows:

Health

- Research has demonstrated that people with learning disabilities have greater health needs and poorer health outcomes than the general population
- There is considerable evidence, discussed in more detail later in this document, that people with learning disabilities do not receive the same healthcare as other people⁹ and they report more significant and ongoing health inequalities¹⁰.
- Despite higher rates of mortality and morbidity, they experience shortfalls in the provision of and access to healthcare.¹¹

Housing

- People with learning disabilities are less likely to live in a home of their own choosing and to choose who they live with
- Only 15% of people with learning disabilities have a home of their own
- More than 30% of people with learning disabilities live in residential care homes, a significant proportion of which are some distance away from their place of origin and their families

Employment

- People with learning disabilities, who want to work, are less likely to have a job
- Only one in ten of those known to social services has any form of paid employment, and of those only very few work more than 16 hours

Having a life

- People with learning disabilities are less likely to have choice and control over the support they need in their daily lives; and are less likely to have choice and control over what they do during the day – attending college, having relationships, socialising for example.

Inclusion

- Where delivery of Valuing People has been successful, local delivery has still not sufficiently addressed the needs of all people with learning disabilities, especially those with complex needs, people from BME communities, those with mental health support needs and offenders
- People with learning disabilities have had their human rights ignored
- The Social Exclusion Task Force identified people with moderate and severe learning disabilities as one of the most excluded groups still in our society

⁸ www.dh.gov.uk

⁹ Healthcare Commission and the Commission for Social Care Inspection, Joint Investigation into Cornwall Partnership Trust, July 2006; Healthcare Commission Investigation (2007); Healthcare Commission (December 2007)

¹⁰ *Healthcare for All*, Report of the Independent Inquiry into Access to Healthcare for People with Learning Disabilities (July 2008)

¹¹ “Estimated prevalence of people with learning disabilities: template for general practice” Victoria Allgar, Ghazalal Mir et al, British Journal of General Practice, June 2008.

- People with learning disabilities report that they are often the target of hate crime, that they are dependent on very limited and expensive public transport to get around, and that social isolation is one of the things they fear the most.

Other related strategies and policies

9. One of the *Valuing People Now* objectives is to make change happen across all the policies that impact on people with learning disabilities (employment, housing, transport, communities etc) through the provision of information, evidence and advice to support delivery of related policies. This impact assessment focuses on health and social care and does not cover related strategies and policies. Background information on these policies is included at Annex B including references to impact assessments on individual policies where these are available.

***Valuing People Now* objectives to be delivered within health and social care section**

10. The summary objectives for *Valuing People Now* are to:

- improve the quality of healthcare for people with learning disabilities (Section I - Healthcare)
- make change happen for all people through improving the capacity and capability to support delivery at a regional and local level (Sections II - Support for Delivery and Section III - Better Commissioning)

Summary of options

11. The options for action, which arise out of *Healthcare for All* and the *Valuing People Now* consultation, are set out later in the document. Overall, the options for the Department can be summarised under three headings:

Option 1: Do nothing and stop all action already underway. The action already underway is set out below under **Option 2.**

The issues of poor access to health and poor treatment will remain unchanged if no action is taken. Furthermore, some of the action already underway under *Valuing People Now*, such as the new Directed Enhanced Service (Directed Enhanced Service) on annual health checks, the transfer of commissioning of adult social care from the NHS to local authorities, commissioning local services for local people; and establishing Regional Programme Boards, would have to be reversed and government policy overruled.

People with learning disabilities would continue to fail to have equality of access to healthcare, resulting in some cases in failure to identify health problems and commencement of appropriate treatment at an early stage.. This would potentially lead to increased costs as a result of increased dependence on health and social care support, prescription charges, increased medical appointments/interventions and the increased risk of premature death.

If nothing were done to improve data and information collection, there would continue to be a lack of accurate data regarding the number and needs of people with learning disabilities. This will impact on the ability of commissioners to develop

services that meet the needs of their local population. This may result in additional expenditure on expensive out of area treatments or placements due to a lack of local service. Change would happen but at a slower rate than with additional interventions.

There are potential costs to the NHS should individuals challenge implementation of 'reasonable adjustments' under the Disability Equality duty in terms of their access to health care and quality of care and treatment within the NHS.

Do nothing is however the baseline against which recommendations are compared.

Option 2: Do nothing more than continue action already underway as a result of Valuing People. This includes (the recommendations are set out in *Valuing People Now*):

Healthcare

- Recommendation 1: Training in learning disability awareness made available for all healthcare workers in the acute sector
- Recommendation 2: Increase production of learning disability leaflet
- Recommendation 5: Extend health action planning
- Recommendation 6: Directed Enhanced Service on health checks, training and data collection
- Recommendation 7: Establish acute hospital liaison and primary care facilitation posts in all areas

Social care

- Recommendation 9: Strengthen structure, role and accountability of Partnership Boards
- Recommendation 10: Transfer commissioning and funding of social care for adults with learning disabilities from Primary Care Trusts to local authorities

Option 3: Implement all recommendations under **Option 2** and new recommendations as proposed in *Valuing People Now*. The additional actions are -

Healthcare

- Recommendation 3: Web-based e-learning package
- Recommendation 4: Confidential Inquiry into premature deaths
- Recommendation 8: Public Health Observatory (PHO)

SECTION I - HEALTHCARE

Introduction

1.1 Recent research has shown that the health needs of people with learning disabilities have not been properly addressed by the NHS. Broadly, the evidence shows that, despite higher rates of mortality and morbidity¹², people with learning disabilities continue to experience shortfalls in the provision of and access to healthcare^{13 14}.

1.2 Firstly, research has found that people with learning disabilities have unmet need for healthcare. For example, research in Wales shows that levels of unmet need are relatively high. The 'Primary care, Evaluation Audit and Research in Learning disabilities' (PEARL) study in 2005 by the Welsh Centre for Learning Disabilities¹⁵ found that of 181 people with learning disabilities who underwent a health review, over half had a new health need identified. The health issues included diabetes, hypertension, high cholesterol, thyroid disorders, dental problems, cardiac difficulties, asthma and mental health difficulties¹⁶ as well as sensory impairments^{17 18}. A study by Halstead *et al*¹⁹ showed that behavioural disturbance and disability were better predictors of a low volume and poor quality of primary care than the client's location, that is whether in the community or in residential care.

1.3 Secondly, there is evidence of higher rates of mortality (number of deaths) and morbidity (prevalence of disease) amongst people with learning disabilities. In 2006 the Disability Rights Commission (DRC) published the report of its formal investigation into inequalities in physical health experienced by people with mental health problems and those with learning disabilities²⁰. It showed that people with learning disabilities "die younger than other citizens" and had high rates of unmet health needs, "which may contribute to early death." The report highlighted a "fatal complacency" in the NHS which had contributed to this situation. Another study, on access to secondary healthcare for people with a learning disability²¹, estimated that 26% of people with

¹² Alborz, A., R McNally, Caroline Glendinning (2005) 'Access to health care for people with learning disabilities in the UK: mapping the issues and reviewing the evidence', *Journal of Health Services Research & Policy*, Vol.10(3), 173-182, 1355-8196

¹³ "Estimated prevalence of people with learning disabilities: template for general practice" Victoria Allgar, Ghazalal Mir *et al*, *British Journal of General Practice*, June 2008.

¹⁴ Straetmans, J.M.J.A.A., Schroyen Lantman-de Valk, H.M.J. van, Schellevis, F.G., Dinant, G.J. Health problems of people with intellectual disabilities: the impact for general practice. *British Journal of General Practice*: 57, 2007, nr. 534, p. 64-66

¹⁵ The 'Primary care, Evaluation Audit and Research in Learning disabilities' (PEARL) study by the Welsh Centre for Learning Disabilities 2002

¹⁶ Baxter H, Lowe K, Houston H, Jones G, Felce D, Kerr M. Previously unidentified morbidity in patients with intellectual disability. *British Journal of General Practice*. 2006; (56): 93-98.

¹⁷ Mental Retardation and Developmental Disabilities Research Reviews Vol 12 Issue 1 pp 28-40 2006 'Vision and oral health needs of individuals with intellectual disability, Pamela L. Owens, Bonnie D. Kerker, Edward Zigler, Sarah M. Horwitz (prevalence of vision impairment)

¹⁸ Evenhuis *et al* 2001 (prevalence of hearing impairment)

¹⁹ Halstead S, Milne A, Wright E, Hollins S. Annual primary care contacts by people with intellectual disabilities: a comparison of three matched groups. *Journal of Applied Research in Intellectual Disabilities*. 2000; (13): 100-107.

²⁰ Disability Rights Commission 'Equal Treatment: Closing the gap' A formal investigation into the physical health inequalities experienced by people with learning disabilities and/or mental health needs, 2006

²¹ Band, 1998, Access to secondary healthcare for people who are learning disabled.

learning disabilities are admitted to hospital every year compared with 14% of the general population.

1.4 Further, research suggests that life expectancy is shortest for those people with learning disabilities with the greatest support needs²² and the most complex and/or multiple ('co-morbid') conditions. In a study by Hollins and others²³, 52% of those who died also had respiratory disease compared to 15-17% of those in the general population. Early death amongst people with learning disabilities was significantly associated with cerebral palsy, incontinence, problems with mobility and residence in hospital. Ethnicity also appears to be a factor with morbidity and mortality being higher amongst those with learning disability from a minority ethnic community²⁴.

Healthcare for All and other inquiries/reports

1.5 These issues have been highlighted in a number of recent reports and inquiries. These include:

- The Healthcare Commission and Commission for Social Care Inspection Joint Investigation into Cornwall Partnership Trust²⁵;
- The Healthcare Commission Investigation at Sutton and Merton²⁶;
- The Healthcare Commission, audit of specialist inpatient healthcare services²⁷;
- The Joint Committee on Human Rights report on people with learning disabilities;²⁸ and
- The Report of the independent inquiry into access to healthcare for people with learning disabilities (*Healthcare for All*)²⁹.

The evidence points to three key problems that need addressing to improve access and quality of healthcare for people with learning disabilities:

:

- A poor understanding amongst healthcare professionals of the special needs of people with learning disabilities;
- Low take up of screening programmes and health checks;
- Insufficient data and information.

²² Bittles AH, et al. The influence of intellectual disability on life expectancy. *Journal of Gerontology Series A Biological Sciences and Medical Sciences*. 2002; 57(7):470-472.

²³ Hollins S, Attard MT, von Fraunhofer N, Sedgwick P. Mortality in people with learning disability: risks, causes, and death certification findings in London. *Developmental Medicine & Child Neurology*. 1998; (40): 50-6.

²⁴ Ghazal Mir, Andrew Nocon and Waqar Ahmad, with Lesley Jones, *Learning Difficulties and Ethnicity: Report to the Department of Health* 2001

²⁵ Joint investigation into the provision of services for people with learning disabilities at Cornwall Partnership NHS Trust by the Commission for Social Care Inspectorate and the Healthcare Commission. London: Commission for Healthcare Audit and Inspection 2006

²⁶ Commission for Healthcare Audit and Inspection: Investigation into the service for people with learning disabilities provided by Sutton and Merton Primary Care Trust. London, 2007

²⁷ A life like no other: a national audit of specialist inpatient healthcare services for people with learning difficulties in England Healthcare Commission 2007

²⁸ Joint Committee on Human Rights: *A life like any other*, March 2008

²⁹ Sir Jonathan Michael, *Healthcare for All*, Report of the Independent Inquiry into Access to Healthcare for People with Learning Disabilities, DH, July 2008

1.6 This section of the impact assessment, covering healthcare, looks firstly in detail at these three key problems and the evidence for them. Next, each recommendation is described in more detail with progress in addressing the problems. Then costs are discussed as well as the benefits. Finally, it considers how Options 2 and 3 address each of the three problems with risks involved. The recommendations of *Healthcare for All* have been included, where appropriate, in the options described below.

Three key problems in existing healthcare

i. There is generally poor understanding on the part of healthcare professionals of the health needs of people with learning disabilities. This, as well as poor practice in their healthcare, can lead to avoidable premature deaths.

1.7 Many health professionals have insufficient understanding of the health, quality of life and other needs of people with learning disabilities, or those of their carers. They also have a limited understanding of how to address the difficulties of communication and interaction. As a result, people with learning disabilities often do not receive the treatment they need. This is believed to be a contributory factor in the high incidence of preventable premature deaths for people with learning disabilities.

What is the evidence for the problem

1.8 *Healthcare for All* cited evidence that some health service staff, particularly those working in general healthcare, have very limited knowledge about learning disability. Researchers describe how staff without training tend to stereotype people with learning disabilities, are unfamiliar with the legislative framework, and commonly fail to understand that a right to equal treatment does not mean treatment should be the same. The health needs, communication problems, and cognitive impairment characteristic of learning disability in particular are poorly understood by staff³⁰. The Report also found that some staff are not familiar with what help they should provide or from whom to get expert advice³¹. In terms of formal undergraduate training *Healthcare for All* found that only clinical psychology pre-registration training included working with people with learning disabilities³². As a result, the Report concludes that people with learning disabilities suffer poor practice, diagnostic overshadowing³³, ineffective treatment and a higher incidence of premature death³⁴.

1.9 *Healthcare for All* also heard evidence and found research³⁵ that showed that GPs who lack training in learning disability are unlikely to deliver health checks to a good

³⁰ e.g. Margaret Sowney and Owen Barr, *Journal of Learning Disabilities* Vol 8 No3 247-265 (2004) Equity of Access to Health Care for People with Learning disabilities: A concept analysis.

³¹ *Treat me Right!* Mencap, 2004

³² *Healthcare for All* para. 3.2

³³ This is the term used by the Disability Rights Commission and others to describe the tendency for symptoms of ill health to be overlooked or misread because they are attributed to the learning disability.

³⁴ *Healthcare for All* paras. 3.2 and 4.1; See also *Death by indifference: following up the Treat me right! report.* Mencap. London. 2007; *Equal treatment: closing the gap.* Disability Rights Commission. London. 2006.

³⁵ Annette Hames and Tracy Carlson 'Are primary health care staff aware of the role of community learning disability teams in relation to health promotion and health facilitation?' *Journal of Learning Disabilities* Vol 34 Issue 1 pp 6 – 10 2006

standard without support³⁶. Research commissioned by *Mencap*³⁷ found that of 215 GPs 75% had received no training to help them treat people with a learning disability and 90% of them felt that the patient's learning disability had made it more difficult to give a diagnosis.

ii. People with learning disabilities do not fully access health screening or health checks

1.10 There is substantial evidence of barriers to access to health care experienced by people with learning disabilities³⁸. This includes access to primary care and secondary care as well as to screening programmes.

What is the evidence for the problem

1.11 Research³⁹ has shown that uptake for cervical screening amongst women with learning disabilities is far lower than average. Just 3% of women aged 18 and over with learning disabilities living within a family, and 17% of those in formal care have had screening, compared to 85% for women aged 20-64 nationally. Another study of breast cancer screening of older women living in group homes found that they were not routinely undertaken.⁴⁰ A NICE audit in 2002 of deaths amongst people with epilepsy indicated that almost 60 per cent of child deaths and almost 40 per cent of adult deaths were potentially avoidable.

1.12 *Healthcare for All* identified a lack of understanding of legislation, in particular as it applied to the concept in the Disability Discrimination Act of 'reasonable adjustments'. One of the factors preventing access is slow progress in developing suitable primary care services 'reasonably adjusted' for people with learning disabilities.

iii. There is a lack of data and information about people with learning disabilities and their care. This means that commissioners and providers of care do not have relevant information available to them to ensure that services properly meet the needs of people with learning disabilities

1.13 DH recognises that there is insufficient consistent data across a number of equality strands, including for people with learning disabilities. A lack of information about people with learning disabilities is recognised as a major obstacle to assuring good quality services.

What is the evidence for the problem

³⁶ *ibid* para 4.3.1

³⁷ Treat me right – Better healthcare for people with a learning disability Mencap 2004

³⁸ M Kerr, F Dunstan, and A Thapar 'Attitudes of general practitioners to caring for people with learning disability' *British Journal of General Practice* Feb 1996 pp 92-94. M. Kerr, F. Dunstan, A. Thapar, L. Bond 'Attitudes of general practitioners towards health care for people with intellectual disability and the factors underlying these attitudes' *Journal of Intellectual Disability Research* Vol 41 Issue 5 pp 391-400 1997.

³⁹ The NHS – health for all? People with learning disabilities and health care, Mencap, 1998

⁴⁰ Davies N and Duff M (2001) Breast cancer screening for older women with intellectual disability living in community group homes. *Journal of Intellectual Disability Research* 45 253-257.

1.14 A number of studies including *Healthcare for All*, reported significant and ongoing health inequalities, particularly that the special needs of people with learning disabilities were not identified⁴¹. A study by Cassidy *et al*⁴² found that 94% of people with learning disabilities attending their first health check had a physical health problem requiring intervention. *Healthcare for All* took the view that that this is in part due to the lack of good information and data to allow people with learning disabilities to be identified by the health services and their pathways of care tracked.

1.15 *Healthcare for All* also took the view that this lack of information was a key obstacle to delivering and evaluating the effectiveness of health services for people with learning disabilities. It found that it was difficult for services to prepare properly or make the necessary 'reasonable adjustments' if patients' communication and other special needs are unknown and that mistakes can lead to failures of treatment, risks for the patient, and a failure to engage other partners, including carers, in the treatment plan. Such mistakes were described in the 2002 NICE audit of sudden unexpected but potentially avoidable deaths in children and adults with epilepsy, where shortcomings in information exchange were highlighted as a major problem.

1.16 *Healthcare for All* also observed that, while there is a core data set to support Joint Strategic Needs Assessments (Joint Strategic Needs Assessments), with guidance on the process, this is limited to adults with learning disabilities in employment, in settled accommodation and/or receiving (social) services in the community, but had nothing relating directly to health care or health outcomes.

Benefit analysis

1.17 There is no specific research that provides robust evidence of all quantifiable benefits. However, there is evidence of the problems that exist and some evidence of the efficacy of particular interventions in addressing these problems. To help remedy this we are proposing to undertake an evaluation of health checks in particular, as well as other measures to increase the evidence base to inform future policy. These issues are discussed under the particular recommendations below.

1.18 Set out below are the recommendations we are making for each of the problems outlined above, the costs associated with each recommendation together with the benefits of each recommendation and evidence of efficacy, where this is available.

Recommendations for Healthcare

Recommendation 1: Training in learning disability awareness is made available for healthcare workers in the acute sector

1.19 The *Valuing People Now* response to Recommendation 1 in *Healthcare for All* says that training should be reviewed and improved for all healthcare staff in line with

⁴¹ Martin, G, 2003. Annual health reviews for patients with severe learning disabilities: five years of a combined GP/CLDN clinic. *Journal of Learning Disabilities* (London) 7 (1), 9-21

⁴² Cassidy, G, Martin, Dm, Martin, Ghb, Roy, A, 2002. Health checks for people with learning disabilities: community learning disability teams working with general practitioners and primary health care teams. *Journal of Learning Disabilities* (London) 6 (2), 123-136.

best practice to address the needs of people with learning disabilities. For the purposes of assessing the impact of this training the following were taken in to account. Firstly, that the training needs of staff working GP practices will be met under the new Directed Enhanced Service (Directed Enhanced Service) on health checks (see Recommendation 6 below which includes costings). Secondly, the training needs of specialist learning disability health teams and community teams is already being met. The training under this recommendation is therefore aimed at clinical staff working in the acute sector.

1.20 Training is required for all existing clinical staff in the acute sector. Funded training will take place over three years, after which any top up training will be incorporated into equalities Continuing Professional Development (CPD). After three years, new clinical staff should have learning disability included in their undergraduate professional training. (See Recommendation 1 *Healthcare for All* and under section on What progress has been made already to implement these recommendations below). One third of staff will be trained in each year from 2009/10. Staff will be offered a two hour session employing specialist lecturers (for example people with a learning disability and family carers supported by liaison nurses/facilitators or CPD trainers). The cost for each session is estimated at £60.

1.21 Strategic Health Authorities are asked to account to the Department at year end, in a one-off exercise, to confirm that this training is set up and that service users and carers have been involved in the design and delivery of the training. For future years, Strategic Health Authorities will report on this training under the Strategic Health Authority Learning Disability Performance and Self Assessment Framework⁴³ for services for people with learning disabilities which is being developed and will include this performance measure.

1.22 No additional costs should arise from the requirement on Strategic Health Authorities to account for this training to DH via the Self Assessment Framework. If there are any additional costs these could be funded from the 'Strategic Health Authority bundle' for 2008/9.

Costs⁴⁴: See basis for assumptions at Annex C. The cost of training is about £0.6m per year. The opportunity costs have been estimated at £2.6m - £10.4m for the first year rising as the result of wage inflation over the three year period. Liaison nurses may reduce the cost by up to £1.3m per year.

The net annual total cost of training is between £1.9m and £11.4m.

Benefits:

Addressing key problem i. There is generally poor understanding on the part of healthcare professionals

- There will be an increase in the quality of healthcare experience for people with learning disabilities and their carers with greater awareness of their needs by staff in the acute sector.

⁴³ Developed by Jackie Sochocka, Health & Social Care Consultant

⁴⁴ all costs given in 2009/10 prices

- Changes in attitude and practice by clinical staff in the acute sector which may lead to fewer unnecessary referrals and procedures which will have cost savings and be less stressful for people with learning disabilities.
- Clinical staff will be better informed and this may lead to more accurate diagnosis.
- Better diagnosis and screening will lead to better health and quality of life for people with learning disabilities as well as potentially fewer deaths.

Recommendation 2: Increase production of learning disability leaflet

1.23 The Royal Colleges have already developed a learning disability leaflet, 'Treat Me Right' targeted at healthcare clinicians. We recommend funding an increase in the number of leaflets and to support marketing. The impact of doing so will be high given the Royal College's influence in this field. As such this will be a cost-effective option involving minimal additional cost as all the start-up costs have already been covered. It can be used by healthcare staff in the primary and secondary sectors to supplement other training.

Cost: There are no set up costs as the leaflet is already in production. Annual costs have been estimated at £13k for marketing and production.

Benefits:

Addressing key problem i. There is generally poor understanding on the part of healthcare professionals

- Greater level of awareness of issues, amongst all clinical staff, from a respected source.
- Supplements other forms of training, e-learning and face-to-face in a format that can be easily updated.

Recommendation 3: Web-based e-learning package

1.24 We recommend the development of a web based e-learning package to provide training to health professionals and support staff as part of continuing professional development in both the primary and secondary sectors.

Costs – managing and maintaining the web-site would cost about £4k per annum. Initial set up costs would be at a one-off cost of £35k. Total Cost: £39k in Year 1 and £4k thereafter.

Benefits

Addressing key problem i. Poor understanding on the part of healthcare professionals

1.25 This recommendation would benefit those health professionals practising in remote areas and provides a flexible adjunct to face-to-face training. It would supplement the training proposed under *Valuing People Now* in the acute and primary care sectors

Recommendation 4: Confidential Inquiry into premature deaths

1.26 This recommendation provides a response to the *Healthcare for All* recommendation that the Department should 'raise awareness of the risk of premature avoidable death for people with learning disabilities'. HFA proposes that this is undertaken through a series of measures, supplemented by a time-limited confidential Inquiry into premature deaths to provide evidence for clinical and professional staff of the extent of the problem and guidance on prevention.

1.27 The confidential inquiry will provide clear academic evidence and identify patterns/ indicators. These can then be translated into formal and measurable standards and clinical guidelines to improve all aspects of practice within the NHS in respect of supporting people with learning disabilities to have equal access and better health treatment and support. The outcome of the inquiry would also improve the clinical evidence base that should underpin commissioning of local services. In summary the outcomes will be used to inform and change clinical practice.

1.28 The National Patient Safety Agency (NPSA) drew up a business case for a confidential inquiry in October 2008.⁴⁵ The business case identified two main reasons for an inquiry:

- to define and better understand a high early mortality rate in a defined group of people with a learning disability
- to better understand how and where clinical intervention may be insufficient, ineffective, or harmful.

1.29 The NPSA identified three basic stages common to all confidential inquiries: case identification; the collection of case information; and case review in order to reach conclusions about care and how it might be improved. The NPSA appraised a series of options (including a no inquiry option). These ranged from a comprehensive inquiry, investigating every case with a large range of additional studies at a cost of £5m over three years. A second option was a focussed inquiry, based on the collection of death statistics and a large sample of these at a cost of £3m over three years. Finally, there was the option for a study that dispensed with any review of incident cases and concentrated instead on a prospective study which might benefit those caring for people with learning disabilities at a cost of £2m.

1.30 The NPSA scoping study indicated that the costs of any of their options would exceed £2m and a full tender exercise is therefore necessary (rather than commissioning this work from NPSA) with bids invited from other organisations including those in Europe.

Costs – the NPSA's business case presented several scenarios with estimated costs ranging from £2m to £5m, including the cost of the tender. Set up costs of about £0.5m are anticipated in year 1 with the remaining costs split between years 2 and 3.

⁴⁵ Stoddart S & Stevenson E, unpublished, 'Business Case for a Confidential Inquiry into Premature Deaths in Patients with a Learning Disability' NHS National Patient Safety Agency, October 2008.

Benefits:

Addressing key problem i. Poor understanding on the part of healthcare professionals

- Outcomes of the CI may result in earlier identification of conditions leading to better health outcomes and a reduction in unnecessary suffering (see the PEARL⁴⁶ study in Wales where health checks identified high levels of undiagnosed health conditions.) It would also be expected to provide evidence of good practice and interventions and standards to help support the care of people with learning disabilities.

Recommendation 5: Extend health action planning

1.31 Health Action Plans for people with a learning disability was a requirement under Valuing People 2001 but many localities did not fully implement this requirement. It has been estimated that in places where there is good investment (for example, by having a strategic health facilitator post), health action planning is carried out for up to 60% of people with a learning disability known to local services. This may take place for only 10% of people in areas where investment is low. Health action planning will form a natural part of annual health checks (as a reasonable adjustment for communicating health needs and health actions). After the initial set up costs, any additional action will be picked up through the health check process.

1.32 Health checks should integrate with the patients' personal health record or Health Action Plan (HAP). In addition, it is good practice for HAPs to be maintained for everyone with a learning disability who has a health check (that is, those known to local authorities) to ensure people understand their own health needs and the actions they need to take to stay healthy. In this way, health professionals will be helped to meet the requirements of the Disability Discrimination Act, to make reasonable adjustments through accessible information.

1.33 People with a learning disability will benefit by having an up to date plan informed by an annual health check. The plan should include health surveillance/screening records, health promotion (smoking cessation, weight control), action focussed on individual health needs, mental health needs and so on. For the individual and their carers, the benefits of a health action plan are that everything to do with their health is gathered together, and once in place, they are easy to update – either on an annual basis alongside health checks or more often where the individual has complex needs.

1.34 Supporting the health needs of people with learning disabilities is an activity that currently rests mainly with informal carers, with support from primary care and specialist health professionals and social care support workers. Health action planning will replace some of that current activity on an ongoing basis, and no new ongoing additional burden is anticipated. Additional time for social care professionals to support people with profound disabilities understand their health needs and lead healthy

⁴⁶ The 'Primary care, Evaluation Audit and Research in Learning disabilities' (PEARL) study by the Welsh Centre for Learning Disabilities 2002

lifestyles is part of person centred planning. We expect this to be covered within the Transforming Social Care funding made available to local authorities to deliver *Putting People First* - a 'core component' of which is person centred approaches.

1.35 However, there will be some activity for time taken to update the HAPs that falls to health services. Health staff who have contact with people with moderate learning disabilities, such as podiatrists and practice nurses, may need to take more time to make reasonable adjustments to support the person to understand health related actions and help them plan to be healthy. This will vary based on the individual, but we estimate that is likely to add up to roughly 2 hours over the course of a year.

1.36 We have based the cost of this action on a nurse's salary as this is most likely to be the health professional who will update the HAP.

1.37 In terms of accounting for new people, young people coming up through transition should already have a health action plan as part of their transition planning process. Under their Year 9 review, which introduces the person centred transition plan, the school nurse or paediatrician will make an input to establish the HAP. Adults newly identified by services (for example those with older family carers who require more support), should be included in the 240,000 figure as this is a conservative estimate (that is, a slight overestimate) of the current numbers.

Costs - one-off set-up costs for HAPs for people currently known to services over three years is £5.2m to £7.3m. The total cost of maintaining HAPs for people with profound learning disabilities over the three years is estimated to be between £6.2m and £14.6m. For breakdown of spending over the three years see the summary tables. For details of assumptions on which calculations are based see Annex C.

Benefits:

Addressing key problem ii. People with learning disabilities do not fully access health screening/health checks

- Increased awareness of services available for people with learning disabilities and their carers.
- Regular monitoring of access to and take up of screening and checks.
- Reduced preventable health conditions and deterioration in existing conditions.
- Reduced unnecessary use of secondary health services.

Recommendation 6: Directed Enhanced Service on health checks, training and data collection

1.38 Health checks enable early identification and treatment of problems and referrals for appropriate support. DH introduced a new two year Directed Enhanced Service (Directed Enhanced Service), effective from April 2008 and further promoted under *Valuing People Now* in response to *Healthcare for All*, bringing in annual health checks for people with a learning disability known to local authorities. Under the Directed Enhanced Service, GPs and practice staff are required to undergo training, and integrate checks with the individual health action plans of patients on local authority

registers.⁴⁷ The number of people with moderate or severe learning disabilities known to local authorities who receive annual health checks will be a new Vital Signs indicator. The Directed Enhanced Service will be reviewed at the end of March 2009 as part of the GP contract negotiation between NHS employers and the BMA.

1.39 As part of the consideration of the Directed Enhanced Service (and as set out in Recommendation 8 of *Healthcare for All*), we considered the cost of extending annual health checks to all people with a learning disability – including those not yet known to local authorities. This would require substantial investment in identifying people before undertaking the health checks itself. Based on the estimate of one million people in the population with a mild or moderate learning disability who are not known to local authorities and a cost of £100 per check, extending health checks to all people with a mild to moderate learning disability could cost £100 million per year – in addition to the cost of the identification process. There may well be less benefit for people with mild to moderate learning disabilities as their health status is likely to be better and they are more likely to access the care they need without intervention. However the cost relates to identifying people since once identified they will fall under the current Directed Enhanced Service - being known to services.

1.40 There is no robust evidence to show that this will be a cost-effective means of improving access and, further, we have no reliable assessment of how many people not known to local authorities would benefit from – and could be identified or would come forward for – annual health checks. The conclusion reached was that other measures would be better designed to identify those people with a learning disability not yet known to local authorities who would benefit from health action planning and health checks, for example awareness raising and training of healthcare staff under Recommendation 1.

1.41 Information on training for primary healthcare staff, together with good practice examples, is available on the Valuing People website.⁴⁸

Evaluation of the Directed Enhanced Service

1.42 We recognise the need to ensure that health checks, introduced under a new Directed Enhanced Service from April 2008 and further promoted under *Valuing People Now* in response to *Healthcare for All*, are effective and provide value for money. As a result, by June 2009 we will assess how best to evaluate health checks under the Directed Enhanced Service and the contribution they have made to health action planning and care planning. In the light of this assessment, we will commission a formal independent evaluation of the costs, benefits and cost-effectiveness of health checks. This evaluation, which we estimate will cost up to £0.5m, will provide evidence for decisions about continuation of health checks under the Directed Enhanced Service or otherwise.

Costs – the one-off cost of training primary healthcare staff under the Directed Enhanced Service over 3 years is estimated to be £1.4m per year. The cost of

⁴⁷ Guidance can be found at: <http://www.pcc.nhs.uk/36>

⁴⁸ <http://valuingpeople.gov.uk/dynamic/valuingpeople144.jsp>

health checks carried out over 3 years is estimated to be between £35.9m and £119.6m. The likely estimate is £60.7m. For details, see tables and annex C.

Investment of £22 million has already been identified from 2008/9 to fund the Directed Enhanced Service. Up to £2m has been identified to meet training (including any IT training) costs.

GPs will receive £100 funding for each health check they undertake for people with learning disabilities.

Benefits:

Addressing key problem i: Poor understanding on the part of healthcare professionals

- Changes in attitude and practice by clinical staff in the primary sector.
- More informed and accurate diagnosis.
- Fewer unnecessary referrals and procedures.
- Potentially fewer unnecessary deaths.
- Increased quality of experience for people with learning disabilities and their carers.
- Awareness raising for practice nurses will benefit people with learning disabilities. A study by Melville⁴⁹ *et al* showed that only 8% of practice nurses had ever received training on communicating with people with learning disabilities. A follow up study⁵⁰ of 201 practice nurses found that training interventions had a positive impact on knowledge, skills and clinical practice. 81% of staff receiving training were more able to meet the needs of people with learning disabilities; and 67% of those staff made changes in their practice.
- Annual health checks may result in earlier identification of conditions leading to better health outcomes and a reduction in unnecessary suffering. A study in Wales⁵¹ found that of 181 people with learning disabilities who underwent a health review, over half had a new health need identified. The health issues included diabetes, hypertension, high cholesterol, thyroid disorders, dental problems, cardiac difficulties, asthma and mental health difficulties as well as sensory impairments.

Addressing key problem ii: People with learning disabilities do not fully access health screening/health checks

- Improved communication between primary care services and people with learning disabilities.
- Greater take up of checks and screening services.
- Improved monitoring of access and conditions leading to better health outcomes and a reduction in unnecessary suffering.

⁴⁹ C. A. Melville et al 'The outcomes of an intervention study to reduce the barriers experienced by people with intellectual disabilities accessing primary health care services' *Journal of Intellectual Disability Research*, Vol 50 Issue 1 pp 11-17 2005

⁵⁰ Melville et al 2006 quoted in T.Gibson *Practice Nursing*, [Vol. 17, Iss. 12](#), 04 Dec 2006, pp 593 - 596

⁵¹ Welsh Centre for Learning Disabilities – PEARL 1 - Primary care, Evaluation Audit and Research in Learning disabilities 2002

- Evaluation of Directed Enhanced Service will lead to better and more robust information about the benefits of health checks and the interventions that bring provide real benefits

Addressing key problem iii: There is a lack of data and information about people with learning disabilities

- Improved identification and targeting of people with learning disabilities.
- More informed planning for reasonable adjustments in health services.
- Better tracking across different services and sectors.

Recommendation 7: Establish acute hospital liaison and primary care facilitation posts in all areas

1.43 We recommend extending Recommendation 6 so that implementation of the Directed Enhanced Service on health checks is supported by primary care facilitator posts in Primary Care Trusts. In addition, we propose to establish acute hospital liaison roles in Trusts. These posts will also provide support to secure general health services that make reasonable adjustments for people with learning disabilities as set out in the NHS Operating Framework for 2009/10 as well as helping to put in place effective arrangements for communication and partnership working between primary care and other healthcare providers supported as set out in the Framework.

1.44 *Healthcare for All* recommended that liaison staff should work across the spectrum of care (that is, with both primary care services and the acute sector) to improve the quality of health care for people with learning disabilities. Therefore, this recommendation includes a liaison role in acute hospitals to support reasonable adjustments and acute sector training (under Recommendation 1 above) and a primary care facilitation post support training of primary care staff under the health checks Directed Enhanced Service. The cost of the acute liaison role would normally fall to NHS acute trusts, with health facilitator posts falling to Primary Care Trusts. However some liaison/facilitator roles may be shared across Primary Care Trusts and trusts.

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

1.46 The numbers of liaison and facilitator roles have been calculated on the basis of expert opinion, as robust evidence is not available to support specific levels of staffing.

Costs: The cost over 3 years for acute hospital liaison posts is estimated to be between £7.6m and £30.1m, with best estimate being £16.6m. Employment of sufficient healthcare facilitators by end of year 3 is estimated to be between £7m and £36m with a best estimate of £15m. For details see table and annex.

Benefits:

Addressing key problem i. Poor understanding on the part of healthcare professionals

- More effective implementation of training and training outcomes.
- Improved sharing of experience and knowledge between secondary and primary sectors.
- Provision of readily available source of expertise.

Addressing key problem iii. Lack of data and information

- Improved monitoring of continuity and quality across primary and secondary care.

Recommendation 8: Public Health Observatory (PHO)

1.47 We take the view that a Public Health Observatory established for two years from 2010/11, will help Primary Care Trusts embed best practice. Thereafter the good practice set up under the Observatory will be adopted and continued by Primary Care Trusts, primary care, NHS Information Centre and others. We will commission this programme of work either from a stand-alone Public Health Observatory or from one of the existing Observatories.

1.48 The role of the PHO would be to:

- develop expertise and in-depth knowledge
- provide a single point of contact and information source
- publicise significant work
- develop training programmes for health
- evaluate initiatives resulting from *Healthcare for All*

1.49 There are a number of different models for public observatories which will be examined:

- a 'virtual' Observatory, based on the drugs example, attached to a University with a particular interest in this area of research.
- An Observatory hosted by a Primary Care Trust, based on the Obesity Observatory, as a stand-alone organisation with a clear remit and contracts with the regional Observatory.

Costs: using the obesity model with the Observatory based at a Primary Care Trust the cost, including set up costs of between £100k and £500k, over three years is estimated between £340k and £1.8m with a best estimate of £1.56m.

Benefits:

Addressing key problem iii. There is a lack of data and information about people with learning disabilities

- Improved data and information to inform commissioning and delivery of services.
- Input into training for healthcare professionals.
- Increase in reliability and accuracy of data with a single data source

- Improvements in clinical practice as a result of increase in relevant information.

Specifically, there will be:

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

What progress has been made already to implement these recommendations?

1.50 David Nicholson, NHS Chief Executive, wrote to all NHS Chief Executives on 29 June highlighting the publication of *Healthcare for All*. In a further letter, dated 26 November 2008, he asked Strategic Health Authority Chief Executives what plans they had in place for implementing the recommendations in *Healthcare for All* locally, including activity to promote good practice on all aspects of equality, including disability, health checks and training for GP practice staff.⁵² This will help raise awareness among Strategic Health Authority and NHS staff of the health needs of people with learning disabilities.

Recommendation 1 - 7

1.51 DH is working through education commissioners and education providers to review and improve the training provided, in line with best practice, to address the needs of people with learning disabilities and we will encourage the engagement of service users and carers in the design and delivery of this training. We will also continue working with the professional regulatory bodies, who are responsible for setting educational standards for the health and social care professions, to agree what further steps we can each take to support the recommendation.

1.52 In 2007, the Department published a wide-ranging action plan ('Promoting Equality'⁵³) in response to the recommendations of the Disability Rights Commission report. This focussed on promoting the implementation of annual health checks, supported by a framework to help Primary Care Trusts commission enhanced primary care services for people with learning disabilities, including health action plans and health facilitators. DH will be issuing further guidance on health action planning early in

⁵² http://www.dh.gov.uk/en/Publicationsandstatistics/Lettersandcirculars/Dearcolleagueletters/DH_091359

2009, following the national consultation on requirements for health action planning. Health action planning was originally a requirement set out in the 2001 Valuing People and giving priority to certain groups of people with a learning disability including those in transition to adulthood, those with complex needs, the elderly and members of black and ethnic minority groups.

1.53 DH has recently reached agreement with the British Medical Association to introduce a Directed Enhanced Service for annual health checks for people with learning disabilities known to local authorities. This will be effective from April 2008. This will mean that all Primary Care Trusts in England are under a direction to commission annual health checks from GP practices in their area and to arrange appropriate training for GPs and GP practice staff. These arrangements will initially run until 31 March 2010. The number of people with moderate or severe learning disabilities known to local authorities who receive annual health checks will be a new Vital Signs indicator. Over 2009-2010, we will work with groups representing patients, families and carers and professional groups to review the effectiveness of these arrangements and consider improvements for the future.

1.54 The NHS Operating Framework for 2009/10 reinforces the need for Primary Care Trusts, in line with the recommendations in *Healthcare for All*, to ensure they secure general health services that make reasonable adjustments for people with learning disabilities. It also seeks effective arrangements for communication and partnership working between primary care and other healthcare providers to improve the overall quality of health care for people with a learning disability. DH will work with Strategic Health Authorities to review progress in making these improvements.

Recommendation 8

1.55 DH intends to involve the group chaired by the DH Permanent Secretary, which is responsible for ensuring improvements in the data, information and information systems used by the NHS to monitor equality of access to health services and equality of health outcomes, to look at ways of improving information systems used by the NHS for people with learning disabilities. In order to identify the changes needed, we will ask the NHS Information Centre to work with the Public Health Observatory for learning disability.

1.56 DH will:

- review the data needed to support policy development and implementation and other information needs, to improve our understanding of the diseases and conditions that have the greatest impact on people in different equality strands
- address that impact as well as the barriers for people in different equality strands to achieving the levels of health, wellbeing and independence many people take for granted, and what action central and local government can take to remove them.

1.57 The minimum dataset for Joint Strategic Needs Assessments, which the Inquiry commended, includes indicators on the number of people with learning disabilities resident in each area, the number in employment and the number in settled accommodation. The minimum dataset also includes an indicator on carers' assessments. The number of annual health checks for people with learning

disabilities known to local authorities will also now be collected as part of the NHS Vital Sign indicators (see Recommendation 1 above).

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

Implications for health of Recommendation 9 – 11 (see below under Sections II and III)

1.59 As part of the World Class Commissioning programme, we are working with selected Primary Care Trusts to help identify and spread best practice in commissioning services to meet the needs of people with learning disabilities, including best practice in needs assessment and in engagement with service users, families and carers and Partnership Boards. This should form part of the Joint Strategic Needs Assessments undertaken with local authorities and other community partners. This also includes working in partnership with healthcare providers, for instance through systems of strategic health facilitation and acute liaison, to help ensure that people with learning disabilities receive timely, convenient access to the full range of services needed to meet their health needs. It will also help them to receive personalised and joined-up care across primary care, community health services and hospital settings.

How the recommendations address the problems we have identified

Option 2 - action already underway as a result of *Valuing People Now*:

Recommendation 1: training in learning disability awareness made available for healthcare staff in the acute sector

Recommendation 2: increase production of learning disability leaflet

Recommendation 5: extend health action planning

Recommendation 6: Directed Enhanced Service on health checks, training and data collection

Recommendation 7: Establish acute hospital liaison and primary care facilitation posts in all areas

i. There is generally poor understanding on the part of healthcare professionals of the health needs of people with learning disabilities. This, as well as poor practice in their healthcare, can lead to avoidable premature deaths

1.60 A study by Melville *et al*⁵⁴ showed that only 8% of practice nurses had ever received training on communicating with people with learning disabilities. A follow up study⁵⁵ of 201 practice nurses found that training interventions had a positive impact on knowledge, skills and clinical practice. 81% of staff receiving training were more able to meet the needs of people with learning disabilities; and 67% of those staff made changes in their practice. There was a statistically significant increase in knowledge following intervention and the self-efficacy (perceptions of one's skills in a

⁵⁴ C. A. Melville et al 'The outcomes of an intervention study to reduce the barriers experienced by people with intellectual disabilities accessing primary health care services' Journal of Intellectual Disability Research, Vol 50 Issue 1 pp 11-17 2005

⁵⁵ Melville et al 2006 quoted in T.Gibson Practice Nursing, [Vol. 17, Iss. 12](#), 04 Dec 2006, pp 593 - 596

certain domain) was greater in the groups who received training. Participation in the training groups was associated with a significantly greater change in knowledge and self-efficacy than only receiving the training pack.

1.61 There is also evidence that a greater understanding of the needs of people with learning disabilities can lead to a more positive attitude towards them. For example, one study involving 34 nurses found that graduate nurses and those with high contact with people with learning disabilities had a greater understanding of their needs than non-graduate nurses or those with little or no contact.⁵⁶ One study⁵⁷ followed up 46 hospital staff after training and found that all attendees found the training valuable, while follow up questionnaires showed that the training had improved attendees level of knowledge as well as confidence in dealing with people with learning disabilities.

1.62 Recommendations 1 (acute sector training), 2 (leaflet), 3 (web based training under option 3) and 6 (Directed Enhanced Service on health checks and primary care training) together provide a package of training for healthcare staff on the needs of people with learning disabilities. Recommendation 8 (under option 3), setting up a Public Health Observatory, also contains the expectation that the Public Health Observatory would help develop training programmes for health.

1.63 While *Healthcare for All* has raised awareness among specialist professionals, this is not likely to reach a sufficiently wide generalist audience or provide sufficient momentum to ensure future training and information needs are met. As the research quoted above indicates, a better understanding of the needs of people with learning disabilities will lead to better and more efficient diagnostics and fewer unnecessary referrals. This will save clinicians' time and that of other staff and unnecessary procedures including diagnostics. It will also lead to earlier and better identification of health needs of people with learning disabilities⁵⁸ and help prevent unnecessary suffering.

1.64 Involving service users and carers in the design and delivery of this training will provide the NHS with increased contact with people with a learning disability and their carers and greater familiarity with their concerns. There will be an increase in the opportunity for engagement of people in the local community, social inclusion and employment. The training provided is more likely to meet the needs of people with learning disabilities and accurately reflect carers' experiences and needs if they are involved in its design and delivery.

Risks:

- not all areas will establish acute hospital liaison posts so there will be variable activity on health action planning and acute sector training
- not all GP practices will access training for practice staff and awareness levels will be uneven across the country

⁵⁶ Slevin E, Sines D. Attitudes of nurses in a general hospital towards people with learning disabilities: influences of contact and graduate, non-graduate status, a comparative study. *Journal of Advanced Nursing*. 1996; (24): 1116-1126..

⁵⁷ McMurray and Beebee 2007 *Learning Disability Practice*, 2007, 10, 3 p.10-14

⁵⁸ Felce et al, *The Impact of Repeated Health Checks for Adults with Intellectual Disabilities*, *Journal of Applied Research in Intellectual Disabilities* vol 21, issue 6, Nov 2008 pages 585-596

- the momentum could be lost when *Valuing People Now* becomes more settled, leading to complacency among professional staff and services failing to respond to the needs of people with learning disabilities
- leaflets will not be distributed widely enough and they may be disregarded
- there will be limited improvement overall in the awareness of health professionals of the needs of people with learning disabilities
- other activities undertaken by staff will not be carried out while training takes place
- this training may take the place of other training, or reduce the opportunity for training in other areas of work
- training will be seen by staff as an additional burden rather than an opportunity. This of itself may lead to negative attitudes on the part of staff towards people with learning disabilities

ii. People with learning disabilities do not fully access health screening or health checks

1.65 We are currently finalising the Directions for the health check Directed Enhanced Service and the other four clinical Directed Enhanced Services and they will be published once consultation with the BMA on the wording of the Directions has been concluded. Primary Care Trusts locally will have to be satisfied that GP practices have put in place the requirements under the new Directed Enhanced Service to monitor annual health checks and the training component. The directions will set out the requirements that practices should meet and it is for the PCT to satisfy itself that practices are meeting those requirements. Guidance on the Directed Enhanced Service has already been published⁵⁹ - and further guidance will be issued on the codes that individual practices can use to record their activity under the Directed Enhanced Service.

1.66 As a result of the extension of health action planning to everyone with a learning disability known to local authorities (i) monitoring and treatment for ongoing health conditions will be improved and further deterioration prevented, and (ii) access to all health screening checks, health promotion and activities to maintain health will all be improved. Longer term, action plans will help reduce reliance upon secondary health services and reduce associated costs and reduce preventable health conditions and diseases.

1.67 Under the 2009/10 Operating Framework, and with the support of liaison and facilitation posts, Primary Care Trusts will take action to ensure reasonable adjustments are made to support access to health services for people with learning disabilities. Furthermore, partnership working will be enhanced and appropriate linkages made so that the overall quality of healthcare is improved. Annual health checks will be introduced for all those known to local authorities.

1.68 Under this measure, people are more likely to use and access benefits (in terms of health outcomes) from health services; it should result in better communication and tracking of service users as they access different health services. This will result in

⁵⁹ <http://www.pcc.nhs.uk/36>

saving in time of health staff and in better outcomes for the service user and their family.

1.69 Primary care facilitator posts, based in Primary Care Trusts, were set up under *Valuing People* 2001. They are a source of local expertise, act as a quality monitor track and trend issues arising from groups rather than individuals. Acute hospital liaison posts will support the provision of training in acute services, supporting hospitals to ensure they are meeting their disability equality duty and that the needs of people with learning disabilities are specifically address. They will ensure continuity of communication aids and information between primary and secondary care, using learning and improving future experiences. They will also improve links between primary and secondary care for people with learning disabilities and help ensure that people are signposted correctly.

1.70 Acute hospital liaison posts will improve communication and on site specialist advice and support enabling general hospital staff to better meet the needs of people with learning disabilities in acute hospitals. They might also prepare people with learning disabilities prepare for planned hospital admissions or outpatient appointments which will mean a reduction in 'did not attend'/missed appointments.

Risks:

- GP practices will not contact everyone known to social services with a learning disability and not everyone will receive a health check
- Health checks may become more of a process than a serious attempt to improve the health of people with learning disabilities
- There may be a large increase in the number of conditions diagnosed leading to a further burden on secondary care
- People with learning disabilities and their carers may be reassured by health checks and as a result not go to their GP with new symptoms
- Some people with learning disabilities may not wish to visit their GP even with the encouragement of liaison staff
- Not every area will have a health facilitator post and health action plans will not be developed for everyone
- Reasonable adjustments will take time to establish; as a result people with learning disabilities will not always have access to the secondary care they may need
- Health checks and HAPs may take more time than anticipated, thereby taking time that might otherwise have been used for other activities.
- Health checks may prove to be ineffective for some people, thereby potentially diminishing the impact of the programme as a whole

iii. There is a lack of data and information about people with learning disabilities and their care. This means that commissioners and providers of care do not have relevant information available to them to ensure that services properly meet the needs of people with learning disabilities

1.71 Implementation of Recommendation 6 of *Healthcare for All*, the Directed Enhanced Service on health checks, will provide GPs with improved disability data collection (through accurate READ coding on registers) and this will:

- (i) provide the beginnings of an accurate population profile relating to the number of people with learning disabilities in local practices and PCT areas;
- (ii) help to identify people with learning disabilities and ensure they are offered additional support (in terms of reasonable adjustments) when using health services;
- (iii) help to track people as they are referred to and use different health services;
- (iv) provide both health and social care commissioners with up to date information. This will help to accurately inform the planning (Joint Strategic Needs Assessment) and commissioning of future services to meet the needs of their local population.

Risks:

- Not all GPs will input data which will lessen the validity of central information
- Services will not accurately reflect local population of people with learning disabilities if information is not input accurately by GP practices
- Data input about the degree of learning disability of individual patients may be inaccurate and/or inconsistent across different practices and regions, leading to poor information nationally
- Time spent collecting this information may lead to less time being available to undertake other activities

Summary Healthcare Costs Option 2

£ 2009/10 prices	PV	Best Estimate		
		2009/10	2010/11	2011/12
Ongoing Costs				
Learning disabilities leaflets	£38,000	£13,000	£13,000	£13,000
Health Action Plans (maintaining HAPs)	£10,900,000	£2,500,000	£3,500,000	£5,300,000
DES (healthchecks)	£58,600,000	£18,600,000	£20,200,000	£21,900,000
Liason Nurse	£15,900,000	£3,500,000	£5,800,000	£7,300,000
Health facilitator	£14,500,000	£3,200,000	£5,200,000	£6,700,000
Total Running Costs	£99,938,000	£27,813,000	£34,713,000	£41,213,000
One-off costs				
Training Acute Sector - cost of training and backfill	£5,600,000	£1,900,000	£1,900,000	£2,000,000
Health Action Plans (Set up costs)	£5,900,000	£1,000,000	£1,900,000	£3,300,000
DES (training)	£4,100,000	£1,400,000	£1,400,000	£1,400,000
Total One-off Costs	£15,600,000	£4,300,000	£5,200,000	£6,700,000
Total Costs	£115,538,000	£32,113,000	£39,913,000	£47,913,000

Option 3 – new recommendations as proposed in VPN:

- Recommendation 3: web-based e-learning package
- Recommendation 4: confidential inquiry into premature deaths
- Recommendation 8: Public Health Observatory (PHO)

Addressing key problem 1: poor understanding on the part of health professionals

1.72 Recommendation 3: The web-based e-learning package will supplement the other training measures under option 2 in the primary and secondary sectors. As a stand-alone measure a web-based module would be insufficient to meet the training needs identified in *Healthcare for All* and VPN. We are therefore making this recommendation as an adjunct to the other training proposed. It is a useful vehicle for keeping information up to date and for refresher training as part of professionals' continuing professional development

Risks

- will not be used – staff have little time for self supported training
- will be ineffective without on-job training
- will require considerable resource to keep standard and currency required to support change in practice and gain recognition of staff

1.73 Recommendation 4: The proposed confidential inquiry will provide information about healthcare interventions for people with learning disabilities, with a focus on premature death, to all healthcare staff as well as those responsible for commissioning services. This will help staff understand better the needs of people with learning disabilities, raise awareness of these needs and inform future practice and commissioning.

Risks

- the confidential inquiry will not produce sufficient or sufficiently robust evidence to support changes in practice
- difficult to draw meaningful conclusions due to limited number of cases, problems around definitions and, particularly, potential lack of evidence of common clinical issues
- potentially findings will simply reiterate problems already identified
- findings will be out of date by time published as action under VPN will be addressing issues

1.74 Recommendation 8: The proposed NHS Information Centre and the new Public Health Observatory, if linked in with other PHOs and the Department of Health, would be able to provide information to a wider range of bodies considering policy related to health. Benefits of this, if linked to the Confidential Inquiry, would be the provision of clear information and guidance for practitioners leading to better health practice and the prevention of avoidable deaths.

Risks:

- Despite good data and information there will be a lack of change on the ground
- The guidance will be too broad to make a real difference to individual practitioners

Addressing key problem ii: people with learning disabilities do not fully access health screening or health checks

1.75 Recommendation 3: the web-based e-learning package will help address any lack of understanding on the part of health professionals about the importance of encouraging people with learning disabilities to undertake health screening and health checks and the reasons behind the low take-up rate. This will form part of the package of measures to raise awareness among professionals of the needs of people with learning disabilities and the barriers that exist to prevent them from receiving services.

Risks

- The training will not be specific enough to make clear the importance of encouraging people with learning disabilities to take up checks or screening
- People with learning disabilities may still not want to undertake screening or checks even if encouraged to do so

1.76 Recommendation 4: the proposed confidential inquiry will be expected to detect errors or omissions that show a clear causal association with death and provide information to clinical staff about its findings. A confidential inquiry into premature deaths of people with learning disabilities will therefore provide information to all healthcare staff to raise awareness and inform future practice and commissioning, in particular about the interventions that help prevent premature death, including screening.

Risks

- the confidential inquiry will not produce sufficient or sufficiently robust evidence to support changes in practice
- difficult to draw meaningful conclusions due to limited number of cases, problems around definitions and, particularly, potential lack of evidence of common clinical issues
- potentially findings will simply reiterate problems already identified
- the findings will not be sufficiently sensitive to the often multiple, complex health problems faced by some people with learning disabilities and will be reduced in value as a result

1.77 Recommendation 8: the proposed NHS Information Centre and the new Public Health Observatory, if linked in with other PHOs and the Department of Health, would be able to provide information to a wider range of bodies considering policy related to health. Benefits of this, if linked to the Confidential Inquiry, would be the provision of clear information and guidance for practitioners and commissioners, leading to the better commissioning of services including health checks and screening, as well as better health practice and consequently the prevention of avoidable deaths.

Risks

- Despite good data and information there will be a lack of change on the ground
- The guidance will be too broad to make a real difference to individual practitioners or commissioners
- Without other measures people with learning disabilities may still not access health checks or screening

Addressing key problem iii: lack of data and information about people with learning disabilities and their care.

1.78 Recommendation 4: the proposed confidential inquiry will provide information about healthcare interventions for people with learning disabilities to all healthcare staff as well as those responsible for commissioning services.

Risks

- the confidential inquiry will not produce sufficient or sufficiently robust evidence to support changes in practice
- difficult to draw meaningful conclusions due to limited number of cases, problems around definitions and, particularly, potential lack of evidence of common clinical issues
- potentially findings will simply reiterate problems already identified

1.79 Recommendation 8: as discussed above, we will improve data collection and analysis through the NHS Information Centre and the new Public Health Observatory. Through the new DES on health checks, GPs will have improved disability data collection (through accurate READ coding on registers) and this will feed into the PHO with associated benefits outlined above under Option 1.

1.80 The learning disability PHO, the proposed NHS Information Centre and the new Public Health Observatory, if linked in with other PHOs and the Department of Health, would be able to provide information to a wider range of bodies considering policy related to health. This would have the benefit of providing the necessary data and information for consideration when policy is being developed concerning the needs of people with learning disabilities. This was cited as a main benefit in the development of the drugs PHO.

1.81 Benefits will include the time that is saved by PCTs when developing comprehensive JSNAs that include people with learning disabilities. If this work is linked with the Confidential Inquiry the combined effect would include the provision of clear information and guidance for commissioners and practitioners leading to better health practice and the prevention of avoidable deaths. It would also link with the data collected by GPs as part of the new DES on health checks. Further benefits of the PHO would be that it could feed into the european body of evidence⁶⁰.

Risks:

- Not all GP practices will keep accurate records of people with learning disabilities, despite financial incentive to do so
- It will take time to set up a new PHO and gather all relevant data

⁶⁰ <http://www.pomonaproject.org/index.php>

Additional Healthcare Costs for Option 3

£ 2009/10 prices	PV	Best Estimate		
		2009/10	2010/11	2011/12
<u>Ongoing Costs</u>				
Web based e-learning package (running costs)	£12,000	£4,000	£4,000	£4,000
Total Running Costs	£12,000	£4,000	£4,000	£4,000
<u>One-off costs</u>				
Web based e-learning package (set-up costs)	£35,000	£35,000	£0	£0
Confidential Inquiry	£3,800,000	£500,000	£1,800,000	£1,800,000
Public Health Observatory	£1,500,000	£500,000	£530,000	£530,000
Total One-off Costs	£5,335,000	£1,035,000	£2,330,000	£2,330,000
Total Costs				
	£5,347,000	£1,039,000	£2,334,000	£2,334,000

Introduction to sections II and III

2.1 One of the main priorities is making sure that change happens. The next two sections of this impact assessment, Support to Deliver through Partnership Boards and Better Commissioning look at new proposals in *Valuing People Now* strategy, which aim to deliver this priority. The main areas are enhancing the role of Partnership Boards, supporting the delivery of related policies across Government (not covered by this impact assessment), the transfer of commissioning and funding responsibility for social care from Primary Care Trusts to local authorities. The proposals, which will, in the main, have an impact on social care, are considered in terms of the benefits they are intended to deliver with associated costs and savings.

SECTION II - IMPROVING SUPPORT TO DELIVERY THROUGH PARTNERSHIP BOARDS

2.2 When they were set up in 2001, Partnership Boards were designed to oversee and advise on the implementation of the adult aspects of Valuing People operating within the framework provided by Local Strategic Partnerships. Guidance specified that a senior local government officer should chair Partnership Boards and they should also include statutory sector interests, people with learning disabilities and their carers, independent providers, community groups and voluntary organisations. Partnership Boards were also charged with developing effective links with other agencies relevant to the implementation of Valuing People.⁶¹

2.3 Partnership Boards are not statutory bodies but Government does expect other bodies, in particular local Government and the NHS, to consult with them as their main source of information when planning and taking decisions that affect the lives of people with learning disabilities. Their role has been to represent local stakeholders and key partners and provide policy leadership and commissioning support that increase local capacity and capability to deliver.

2.4 The Health Service and Local Authority Circular on Valuing People, issued in August 2001⁶², described the role of learning disability Partnership Boards in facilitating effective local partnership working. Effective Partnership Boards have shown how people with learning disabilities and families can be best involved in important decision-making, encourage effective partnership working to support local delivery and monitor and influence local policies. Annex A sets out a best-practice model for Partnership Boards.

2.5 The high level objective is to bring the effectiveness of all Partnership Boards up to the level of the best. In this way leadership, delivery and partnership structures will be in place that will support the delivery of the outcomes set out in the *Valuing People Now* strategy. This policy measure seeks to bring together key ways to strengthen Partnership Boards, the main vehicle identified to improve local delivery. There is evidence of what makes a good Board and the policy aim is to enable all Boards to meet this standard⁶³.

⁶¹ Ibid.

⁶² 'Valuing People: A New Strategy for Learning Disability for the 21st Century: Implementation' *Health Service Circular / Local Authority Circular HSC 2001/016: LAC (2001)23*

⁶³ See footnote 2.

What is the evidence for the problem

2.6 Two recent research reports – from The University of Nottingham and Speaking Up, Cambridge⁶⁴ found that the effectiveness of Boards was reliant on the commitment of its members, especially at senior officer level. In some places, representation from other key agencies, such as Primary Care Trusts, was poor, and only in 1 in 3 boards were annual targets set against which success could be measured. The reports found that whilst boards have improved the way they involved people and their families overall, often these people and families felt marginalised.

2.7 The report from the University of Nottingham found that under 30% of Partnership Boards had representatives from the Primary Care Trust. Most people who responded to a survey carried out in the course of the study said that Partnership Boards should be given more power to make decisions and to make change happen. A recent article in *Disability and Society*⁶⁵ concluded that Partnership Boards needed clearer lines of accountability to host organisations and clear responsibility for decision-making.

Recommendations for Social Care

2.8 Continuing with the *status quo* will mean that some Partnership Boards may not be fully effective and there is the risk that *Valuing People Now* will not be fully implemented in those areas of the country. Whilst there will be some improvements building on what is already in place locally, the opportunity would be lost to strengthen effective support to delivery.

Recommendation 9: Strengthen structure, role and accountability of Partnership Boards

2.9 *Valuing People Now* seeks to meet the policy objective by outlining a series of local measures to empower local Boards to better fulfil their role. The *Disability & Society*⁶⁶ article looked at three partnership boards and concluded that “Changing the way [Partnership Boards] operate... would involve attending to structure and to power relations. [Partnership Boards] could be organised with a defined membership, clear lines of accountability back to host organisations and clear responsibilities for decision-making”.

2.10 We propose to strengthen structure, role and accountability of Partnership Boards by the following measures:

- a) Regional Programme Boards. To increase the local role and accountability of Partnership Boards, Regional Programme Boards, with a

⁶⁴ ‘The Role & Effectiveness of Learning Disability Partnership Boards’ 2008 by Rachel Fyson & Liz Fox at the School of Sociology & Social Policy at the University of Nottingham commissioned by Mencap and the Learning Disability Task Force and ‘How well are Partnership Boards hearing the voices of people with learning difficulties and family carers?’ January 2008. Commissioned by the Valuing People Support Team and conducted by Speaking Up

⁶⁵ Carol Riddington, Jum Mansell and Julie Beadle-Brown ‘Are partnership boards really valuing people?’ *Disability & Society*, Vol.23, No.6, October 2008, 649-665

⁶⁶ *ibid.* p. 664

strong Strategic Health Authority presence, will be established in all areas. This measure will enhance local Partnership Boards by providing regional support. It will also improve monitoring with a clear line of reporting from Partnership Boards to *Valuing People* Regional Leads to Deputy Regional Directors of Social Care and Care Partnerships. The role of Strategic Health Authorities will be enhanced by requiring an Authority presence in addition to local authority and stakeholder involvement in Regional Programme Boards. In total nine Regional Programme Boards will be needed across England. Three Boards have already been established and the assumption here is that the remaining six Boards will be established using existing baseline funding.

Costs: Regional Programme Boards - about £42k per annum. This cost will fall to local authorities.

b) Closer working between Primary Care Trusts and Partnership Boards - The evidence from The University of Nottingham study, is that less than 30% of Partnership Boards are attended by Primary Care Trust representatives. To promote better Partnership Board working and increase attendance by Primary Care Trust representatives at meetings, we propose that all Partnership Boards have a Primary Care Trust representative at all meetings.

Cost to Primary Care Trusts is estimated at between £15k and £26k per annum.

c) Strengthen the performance and financial management of Partnership Boards. With support from *Valuing People* Regional Leads, local Partnership Boards are encouraged to review their board membership, processes of engagement and working practices. The recommendation is that Partnership Boards set clear objectives and report regularly, at least annually, to their Regional Programme Boards and that these regular reports are signed off by the self-advocate and family carer representatives on the Board.

d) Strengthen membership of Partnership Boards - The evidence is that those Boards seen to be more effective are usually led by the Director of Adult Social Care, with authentic involvement of local self advocacy and carer leaders.⁶⁷ *Valuing People Now* says that Learning Disability Partnership Boards should be chaired by senior executive members but will require support from more junior staff from the local authority. This support will include writing annual reports and monitoring progress.

e) Partnership Boards to develop scheme for monitoring the implementation of equalities legislation for people with a learning disability - Partnership Boards will be required to develop a scheme to monitor, for example, Equalities Impact Assessments by local authorities for new policies and to ensure the interests of people with a learning disability are covered or are compliant with disability discrimination legislation. It is estimated that Partnership Boards will need a half day to develop a scheme and that this will be a regular agenda item thereafter.

⁶⁷ See previous footnotes on Reports on Partnership Boards.

f) Partnership Boards to implement a *Valuing People Now* awareness campaign – *Valuing People* Regional Leads and Deputy Regional Directors of Social Care to support Boards in running an awareness campaign on *Valuing People Now*. For example, dissemination of *Valuing People Now* Easy Read and leaflets.

g) Partnership Boards to have oversight of Joint Strategic Needs Assessments, Primary Care Trust Commissioning plans and Local Area Agreements. Learning Disability Partnership Boards will be supported by *Valuing People* regional leads to take their place at the centre of local delivery of the key *Valuing People Now* objectives. This will mean building close links between Partnership Boards and the Joint Strategic Needs Assessment process, Local Strategic Partnerships, and the Local Area Agreement; as well as local Overview and Scrutiny Committees. Establishing these formal links may take some administrative and Partnership Board time.

Cost for measures c – g

(i) **£1.4m per annum to fall to local authorities for administrative support, and**

(ii) **between £53k and £212k pa for additional meetings. This will depend on whether all Partnership Boards hold additional meetings.**

TOTAL COSTS TO Primary Care Trusts has been estimated between £96k and £186k with best estimate £149k over three years (this includes about £60k of new costs). The cost to local authorities has been estimated at between £4.3m and £4.7m over three years and the cost to Strategic Health Authorities between £41k and £70k.

Benefits

2.11 Recommendation 9 proposes a range of measures to strengthen the structure, role and accountability of Partnership Boards, building on local good practice and the role of local partners, Strategic Health Authority, Deputy Regional Directors, LAs, in facilitating improved effectiveness.

2.12 These measures will help to ensure that Partnership Boards are properly constituted and led; consulted by statutory agencies; operating in line with good practice advice; involve carers in planning and decision making; and ensure sufficient resources for the operation of the board. Taken together, the measures provide a better defined structure, local role and accountability with a clear line of sight to the new Deputy Regional Directors of Social Care and Care Partnerships and *Healthcare for All*. They provide links to Local Area Agreements (LAAs) and Local Strategic Partnership (LSPs). They improve the accountability, management and membership of individual Partnership Boards and should result in Partnership Boards providing a better and more effective service to people with learning disabilities in the area they serve.

Risks:

- Not all local authorities will send senior official to chair partnership board meetings
- Primary Care Trusts will continue to be under represented at partnership board meetings
- Partnership Boards even if fully constituted will represent the interests of the members' constituencies rather than the common interest of people with learning disabilities

What progress has been made already to implement these recommendations

2.13 Partnership Boards are led by local authorities. The funding and commissioning responsibility for social care for people with learning disabilities will transfer from Primary Care Trusts to local authorities from April 2009. This will strengthen the support for Partnership Boards, when funding and commissioning are fully aligned.

2.14 The Valuing People Support Team have published on their website guidance about what makes a good PB (www.valuingpeople.gov.uk). Speaking Up is developing a Toolkit, commissioned as part of their report, which will be published early in 2009. The Toolkit will be made up of tools and exercises to support each Board to take the next steps and improve their effectiveness.

2.15 Three Regional Programme Boards have already been established to support Partnership Boards and provide clearer lines of accountability. The Cross Government Learning Disability National Programme Board will receive and respond to data around progress, via the Regional Boards, and the Office of the National Director will collate this data, identify potential problem area and agree with the regulatory bodies how best to respond.

SECTION III - BETTER COMMISSIONING

Transfer of funding and commissioning responsibility for social care from Primary Care Trusts to local authorities

Background

3.1 In 2006/7 the Healthcare Commission and Commission for Social Care Inspection published two high profile investigation reports into services provided for people with learning disabilities in Cornwall and Sutton and Merton. In both cases there were findings of serious abuse and failure on the part of the commissioner and/or provider.

3.2 In the statement to Parliament following the publication of the Cornwall investigation, the Government set out a range of actions and commitments at local and national level. This included a commitment to strengthen the commissioning of learning disability services, including consideration of a stronger role for local authorities.

3.3 Current funding arrangements reflect the historical responsibilities of the NHS where the policy of accommodating people with learning disabilities in long-stay hospitals meant the NHS was responsible for all the care needs of those individuals and not just their health needs. Transferring responsibility for learning disability services (other than healthcare) to local authorities, began in 1971. In the 1990s, policy stated that, as people left institutions, commissioning responsibility and associated resources should transfer to local authorities. In many places these changes have been made successfully with authority-led partnerships, via section 256/7 and section 75 arrangements⁶⁸ and pooled budgets.

3.4 *Our health, our care, our say* (2006) made a further commitment to close all NHS learning disability campuses by the end of the decade with associated costs transferred to local authorities. The reprovision of people living in campus accommodation reflects the objective on the National Indicator PSA, on settled accommodation for adults with a learning disability. The 2008/9 NHS Operating Framework included commissioning and funding transfer of social care for adults with a learning disability from Primary Care Trusts to local authorities.

Recommendations for Social Care

Recommendation 10: Transfer commissioning and funding of social care for adults with a learning disability from the NHS to local authorities

3.5 *Valuing People Now* said that, in order that the resources for commissioning learning disability services rest with the authority with lead responsibility, funding and the associated commissioning responsibility for social care would transfer from Primary Care Trusts to local authorities.

3.6 This was generally accepted by 85% of responses to the *Valuing People Now* consultation and is now being implemented.

⁶⁸ Section 256/7 or section 75 of the National Health Service Act 2006 (former 'Health Act flexibilities') such as pooled budgets or lead commissioning arrangements.

3.7 This option is based on local responsibility for negotiating and agreeing the amounts for transfer, and it is anticipated that the proposal will be cost neutral. In most places, (we estimate approximately 80-90% of areas) councils already commission services using a locally arranged transfer from Primary Care Trusts.

3.8 We anticipate that there may be difficulties in some areas (i.e. 10-20% of areas) where they do not currently transfer services, in determining the boundary in spend between specialist healthcare and social care.

3.9 As a result, we anticipate there are two sources of additional costs to the transfer agreement:

- administrative costs of effecting the transfer for Primary Care Trusts and local authorities, which would be one-off costs for areas not currently using arrangements under section 75 of the National Health Service Act 2006; and
- costs to DH of mediating where there are difficulties locally in agreeing the amounts to be transferred.

3.10 Arbitration by the Valuing People Regional Leads might require some 50 to 75 working days, i.e. 0.25 to 0.35 fte staff input. However, account has already been taken of these costs in Care Standards Improvement Partnership business planning and job descriptions, so this will not involve additional cost.

3.11 An estimated 10% to 20% of Primary Care Trusts and partner councils are not currently using section 256/7 or section 75 arrangements. The administrative cost to them of agreeing the amounts to be transferred seems unlikely to exceed £15,000.

Cost - This suggests a total one-off cost for up to 30 Primary Care Trusts and councils of up to £0.5 million.

3.12 A consequence of the transfer is that any savings from better commissioning that had been accruing to the NHS will now accrue to local government. For example, in 2001 *Valuing People* said that people living in NHS residential campuses should have the chance to move. *Our Health, Our Care, Our Say*, January 2006, said campuses should close by 2010 and services should be re-provided for people with learning disabilities in the community. The proposal to ensure commissioning parity with NHS Campus closure is in line with existing policy on campus closure and is covered under continuing care guidance. It does not require PCTs to take immediate action to decommission services but suggests that, when placements come under review, commissioners should follow existing guidelines and avoid commissioning inappropriate types of placements. We estimate a maximum of 200 people with learning disabilities are still inappropriately accommodated in residential health settings. This policy also reflects the objective of the National Indicator PSA on settled accommodation for adults with learning disabilities.

3.13 The pace of people moving out of hospitals, based on the pace of Campus and Old Long Stay Hospital closure, is estimated at approximately 1/3rd per year. This suggests that when the transfer amounts are agreed between local authorities and the NHS, there may still be over 130 people still living in these health settings, therefore

some of the savings would accrue to local authorities, once the final people move in years 2 and 3 of the 3 year period.

3.14 The costs to the NHS of private sector residential accommodation are typically between £465 - £500 per day, equivalent to around £170,000 - £180,000 per year. In contrast, findings from research from Emerson et al suggest that the cost of dispersed housing arrangements is around £77,000⁶⁹. However, this £77,000 figure pertains to a different group of service users. The needs of those people currently costing £170-180K p.a. are likely to be more expensive to meet, as many will be in low secure health settings and will have a history of complex needs and challenging behaviour. Therefore, £77,000 represents a minimum view of the cost of dispersed housing arrangements for these service users currently in NHS-funded private sector residential accommodation. We have assumed, for the highest cost estimate, that annual savings will be 10% of the difference of the two figures. And for the lowest estimate, we have assumed 50% of the difference would be a reasonable maximum. Therefore, a reasonable estimate of the net savings to local authorities is assumed to be between £1.2m and £6.2m up to 2010-11. These costs are conservative because, based on anecdotal evidence, people with complex needs who are well supported and stabilised on a longer term basis may require less intensive crisis intervention.

3.15 This Impact Assessment focuses on the gross costs of implementation. However, these offsetting savings mean that our overall assessment is that there is no net additional cost to local government.

Benefits

3.16 Local authorities have a lead role in delivering the goals set out in *Valuing People Now*. This role will be strengthened when funding and commissioning are fully aligned and we are confident this will result in better services for people with learning disabilities that are tailored around their individual needs. The change will also enable Primary Care Trusts to focus on their primary responsibility of meeting the health needs of people with learning disabilities.

What progress has been made already to implement these recommendations

3.17 Current figures indicate that the NHS spends approximately £2 billion; councils on social care spend £2.6 billion on people with learning disabilities. David Nicholson and David Behan in their letter to Chief Executives in August 2008 asked that Primary Care Trusts and local authorities reach agreement on the amounts to be transferred for 2009/10 and inform the Department by 1 December 2008. This amount will form the basis of negotiation with the Department for Communities and Local Government of the amounts and formula for central allocation from 2011/12.

Risks:

⁶⁹ Drawn from *A Comparative Analysis of Quality and Cost in Village Communities, Residential Campuses and Dispersed Housing Schemes*, Emerson et al, 1998. Updated from 1997/8 to 2006/7 prices using the HCHS pay and prices index.

- Primary Care Trusts will not transfer the whole of funding for social care to local authorities
- Primary Care Trusts and local authorities will be unable to agree on amounts to be transferred
- Local authorities may change commissioning practice with the transfer of social care funding and commissioning to local authorities from April 2009 and some services will be lost that were of benefit to people with learning disabilities

Summary Non-Healthcare Costs

£ 2009/10 prices	PV	Best Estimate		
		2009/10	2010/11	2011/12
<u>Ongoing Costs</u>				
Strengthen role and accountability of Partnership Boards_DH	£30,000	£10,000	£10,000	£11,000
Strengthen role and accountability of Partnership Boards_SHA	£58,000	£20,000	£20,000	£20,000
Strengthen role and accountability of Partnership Boards_PCTs	£140,000	£49,000	£50,000	£50,000
Strengthen role and accountability of Partnership Boards_LAs	£4,400,000	£1,500,000	£1,500,000	£1,500,000
Total Running Costs	£4,628,000	£1,579,000	£1,580,000	£1,581,000
<u>One-off costs</u>				
Transfer of Funding from PCTs to local authorities	£500,000	£500,000	£0	£0
Total One-off Costs	£500,000	£500,000	£0	£0
Total Costs	£5,128,000	£2,079,000	£1,580,000	£1,581,000

Costs

3.18 The costs associated with options 2 and 3 are set out in the following tables:

Summary Option 2

	PV	Best Estimate			Estimated Range	
		2009/10	2010/11	2011/12	Low PV	High PV
<i>£ 2009/10 prices</i>						
<u>Ongoing Costs</u>						
Learning disabilities leaflets	£38,000	£13,000	£13,000	£13,000	£38,000	£38,000
Health Action Plans (maintaining HAPs)	£10,900,000	£2,500,000	£3,500,000	£5,300,000	£5,900,000	£14,000,000
DES (healthchecks)	£58,600,000	£18,600,000	£20,200,000	£21,900,000	£34,700,000	£115,300,000
Liason Nurse	£15,900,000	£3,500,000	£5,800,000	£7,300,000	£7,300,000	£29,000,000
Health facilitator	£14,500,000	£3,200,000	£5,200,000	£6,700,000	£6,900,000	£34,200,000
Strengthen role and accountability of Partnership Boards_DH	£30,000	£10,000	£10,000	£11,000	£30,000	£30,000
Strengthen role and accountability of Partnership Boards_SHA	£58,000	£20,000	£20,000	£20,000	£40,000	£67,000
Strengthen role and accountability of Partnership Boards_PCTs	£140,000	£49,000	£50,000	£50,000	£92,000	£180,000
Strengthen role and accountability of Partnership Boards_LAs	£4,400,000	£1,500,000	£1,500,000	£1,500,000	£4,100,000	£4,500,000
Total Running Costs	£104,500,000	£29,500,000	£36,300,000	£42,800,000	£59,100,000	£197,300,000
<u>One-off costs</u>						
Training Acute Sector - cost of training and backfill	£5,600,000	£1,900,000	£1,900,000	£2,000,000	£5,600,000	£32,500,000
Health Action Plans (Set up costs)	£5,900,000	£1,000,000	£1,900,000	£3,300,000	£5,000,000	£6,900,000
DES (training)	£4,100,000	£1,400,000	£1,400,000	£1,400,000	£4,100,000	£4,100,000
Transfer of Funding from PCTs to local authorities	£500,000	£500,000	£0	£0	£500,000	£500,000
Total One-off Costs	£16,100,000	£4,800,000	£5,200,000	£6,700,000	£15,200,000	£44,000,000
Total Costs	£120,600,000	£34,300,000	£41,500,000	£49,500,000	£74,300,000	£241,300,000
Average Annual Cost (Ongoing)	£36,200,000				£20,500,000	£68,300,000
Costs to Acute Trusts	£21,600,000	£5,500,000	£7,700,000	£9,300,000	£12,900,000	£61,600,000
Costs to PCTs	£94,000,000	£26,800,000	£32,300,000	£38,600,000	£56,600,000	£174,600,000
Costs to LAs	£4,900,000	£2,000,000	£1,500,000	£1,500,000	£4,600,000	£5,000,000
Costs to DH and OGDs	£48,000	£23,000	£13,000	£13,000	£68,000	£68,000

Summary Option 3

	PV	Best Estimate			Estimated Range	
		2009/10	2010/11	2011/12	Low PV	High PV
<i>£ 2009/10 prices</i>						
Ongoing Costs						
Learning disabilities leaflets	£38,000	£13,000	£13,000	£13,000	£38,000	£38,000
Web based e-learning package (running costs)	£12,000	£4,000	£4,000	£4,000	£12,000	£12,000
Health Action Plans (maintaining HAPs)	£10,900,000	£2,500,000	£3,500,000	£5,300,000	£5,900,000	£14,000,000
DES (healthchecks)	£58,600,000	£18,600,000	£20,200,000	£21,900,000	£34,700,000	£115,300,000
Liason Nurse	£15,900,000	£3,500,000	£5,800,000	£7,300,000	£7,300,000	£29,000,000
Health facilitator	£14,500,000	£3,200,000	£5,200,000	£6,700,000	£6,900,000	£34,200,000
Strengthen role and accountability of Partnership Boards_DH	£30,000	£10,000	£10,000	£11,000	£30,000	£30,000
Strengthen role and accountability of Partnership Boards_SHA	£58,000	£20,000	£20,000	£20,000	£40,000	£67,000
Strengthen role and accountability of Partnership Boards_PCTs	£140,000	£49,000	£50,000	£50,000	£92,000	£180,000
Strengthen role and accountability of Partnership Boards_LAs	£4,400,000	£1,500,000	£1,500,000	£1,500,000	£4,100,000	£4,500,000
Total Running Costs	£104,500,000	£29,500,000	£36,300,000	£42,800,000	£59,100,000	£197,300,000
One-off costs						
Training Acute Sector - cost of training and backfill	£5,600,000	£1,900,000	£1,900,000	£2,000,000	£5,600,000	£32,500,000
Web based e-learning package (set-up costs)	£35,000	£35,000			£35,000	£35,000
Confidential Inquiry	£3,800,000	£500,000	£1,800,000	£1,800,000	£1,900,000	£4,800,000
Health Action Plans (Set up costs)	£5,900,000	£1,000,000	£1,900,000	£3,300,000	£5,000,000	£6,900,000
DES (training)	£4,100,000	£1,400,000	£1,400,000	£1,400,000	£4,100,000	£4,100,000
Public Health Observatory	£1,500,000	£500,000	£530,000	£530,000	£340,000	£1,700,000
Transfer of Funding from PCTs to local authorities	£500,000	£500,000			£500,000	£500,000
Total One-off Costs	£21,500,000	£5,900,000	£7,500,000	£9,000,000	£17,500,000	£50,600,000
Total Costs	£126,000,000	£35,400,000	£43,800,000	£51,800,000	£76,600,000	£247,900,000
Average Annual Cost (Ongoing)	£36,200,000				£20,500,000	£68,300,000
Costs to Acute Trusts	21,600,000	£5,500,000	£7,700,000	£9,300,000	£12,900,000	£61,600,000
Costs to PCTs	94,000,000	£26,800,000	£32,300,000	£38,600,000	£56,600,000	£174,600,000
Costs to LAs	4,900,000	£2,000,000	£1,500,000	£1,500,000	£4,600,000	£5,000,000
Costs to DH and OGDs	5,400,000	£1,100,000	£2,300,000	£2,300,000	£2,400,000	£6,600,000

Specific Impact Tests: Checklist

Use the table below to demonstrate how broadly you have considered the potential impacts of your policy options.

Ensure that the results of any tests that impact on the cost-benefit analysis are contained within the main evidence base; other results may be annexed.

Type of testing undertaken	<i>Results in Evidence Base?</i>	<i>Results annexed?</i>
Competition Assessment	No	Yes
Small Firms Impact Test	No	Yes
Legal Aid	No	Yes
Sustainable Development	No	Yes
Carbon Assessment	No	Yes
Other Environment	No	Yes
Health Impact Assessment	No	Yes
Race Equality	No	Yes
Disability Equality	No	Yes
Gender Equality	No	Yes
Human Rights	No	Yes
Rural Proofing	No	Yes

ANNEX A

PARTNERSHIP BOARDS

Best practice model for Partnership Boards⁷⁰

1. Concentrate on developing partnerships all year round
2. Link into local strategic partnerships and inform local area agreements
3. Start from a person-centred approach, thinking about life outcomes for people
4. Are properly supported and resources to do their job well
5. Are co-chaired by a senior, elected executive member of the local authority and a person with a learning disability (and/or family carer)
6. 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
7. Properly support and resource self-advocates and family carers to be influential members of the board.
8. 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.
9. Have meetings that are an event, with a range of techniques used to discuss and deal with issues.
10. Publicise accessible meetings and minutes
11. Set themselves clear objectives and publicly report on what they have achieved (including to the council overview and scrutiny committee and local strategic partnership).

⁷⁰ See 'Valuing People Now: From progress to transformation' March 2008 page 93

ANNEX B

PROVIDING INFORMATION, EVIDENCE AND ADVICE TO SUPPORT DELIVERY OF RELATED POLICIES

A key objective of *Valuing People Now* is to support the delivery of related policies across government which are critical to achieving improved outcomes for people with learning disabilities. Most of the actions set out in *Valuing People Now* involve support to delivery of existing policies through providing information, evidence and advice to other departments via the Valuing People regional leads, the Office of the National Director and the Government Offices in the 9 regions.

Putting People First

A key issue is to ensure that the person centred approach and transformation agenda set out in *Putting People First* applies to all people with learning disabilities.

What is the problem?

Evidence shows that people with learning disabilities and those with complex needs can benefit from the transformation agenda if they receive appropriate support.⁷¹

However, people with learning disabilities do not always have choices that many others take for granted or sufficient control over the support they need. For example,

- direct payments are only 1.1% of total expenditure on learning disability services.
- many people still do not have a person centred plan
- more needs to be done to involve people with complex needs (and their carers) in their own planning.

What are we already doing to address the problem

The Transforming Adult Social Care Programme already includes specific action to ensure inclusion of people with learning disabilities through liaison with the valuing people personalisation and regional leads. This includes building local capacity around *Putting People First* for people with learning disabilities; and government offices prioritising personalisation in delivery support programme. It also includes support for developing the capacity of user led organisations which will support people with learning disabilities and their families.

The work already underway as part of the Transforming Adult Social Care programme, should achieve all the intended outcomes around personalisation, except in relation to supporting local partners to develop local person centred planning strategies. New guidance on person centred approaches is being developed by DH.

Carers

⁷¹www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_076331

Valuing People Now recognises the important role that carers play and the importance of ensuring effective support to carers of people with learning disabilities within the Carers Strategy.

What is the problem?

Consultation on *Valuing People Now* showed that family carers of people with learning disabilities were not routinely involved or recognised as expert partners in the care of their family member. Family carers have argued that additional work is needed to train health and social care professionals to recognise the need to involve family carers, especially for people with complex needs. There are also concerns that the specific needs of people with learning disabilities who are themselves carers (eg for an elderly parent) are not recognised.

What are we doing to address the problem?

The main actions for improving support for carers of people with learning disabilities will be undertaken as part of the Carer's Strategy which was published in June 2008. This sets out the 10 year strategy for all carers including those caring for people with learning disabilities. A separate impact assessment has been published on the Carer's strategy⁷².

The work already underway should achieve all the intended outcomes around carers. In 2008/9 councils received £224m to help them support carers with breaks and other services. Social services departments already have a duty to assess potential service users and carers who are carrying out (or likely to carry out) 'regular and substantial caring'. They review care packages regularly - generally once a year – and carry out additional reviews if the situation for one or other party (or both) changes.

Human Rights

Healthcare for All, the report of an Independent Inquiry into access to healthcare for people with learning disabilities, reported significant and ongoing health inequalities⁷³. The proposals under *Valuing People Now* are aimed at promoting access to services for people with learning disabilities, thus allowing them fully to enjoy their rights and freedoms.

Housing

Many people with learning disabilities do not choose where they live or with whom. More than half live with their families and most of the remainder live in residential care. Only 15% of people have a home of their own and more than 30% of people with learning disabilities live in residential care homes, a significant proportion of which are miles away from their place of origin and their families.

What we are already doing to address the problem

⁷² www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/DH_085345

⁷³ *Healthcare for All*, Report of the Independent Inquiry into Access to Healthcare for People with Learning Disabilities (July 2008)

Much of the work on increasing the number of adults with learning disabilities known to local authorities in settled accommodation is being taken forward under the Public Services Agreement (PSA)¹⁶ which has its own delivery plan. Mainstream housing strategies such as Supporting People will also support increased housing choices for people with learning disabilities

Any new work commissioned as a result of discussions around the joint CLG/DH work programme on housing and people with LD will be subject to appropriate regulatory and equalities impact assessment.

Low Cost Home Ownership

In respect of low cost home ownership, an impact assessment, which included equality and fairness, was done in 2005 as part of the consultation paper prior to the introduction of the HomeBuy scheme.

The government's response is available on the CLG website.⁷⁴

Choice Based Lettings (CBL)

CLG have carried out research looking into the longer-term impacts of CBL - which looked particularly at the impacts on ethnic minority applicants. It produced no conclusive evidence about the impacts on vulnerable applicants, however.

CLG have recently commissioned Herriot Watt University to carry out some research into CBL and vulnerable people - including those with learning disabilities. However, it is not looking at outcomes/impacts, but at the sort of strategies landlords put in place to ensure that CBL works for vulnerable people. The full report (200 pages) and summary are on the CLG website in the CBL section.⁷⁵

Supporting People programme

The *Supporting People* Strategy "Independence and Opportunity" was the subject of an equalities and regulatory impact assessment.

Work, education and getting a life

People with learning disabilities are less likely to have paid employment, to go to college and to have to have active social lives.

Employment

Much of the activity around employment for people with learning disabilities will be carried out through existing programmes of work, including the Getting a Life project. A

⁷⁴<http://www.communities.gov.uk/corporate/?view=Search+results&query=HomeBuy+consultation&contentType=all&sites=all+sites&quickSearch=true&resultsPerPage=20>

⁷⁵ <http://www.communities.gov.uk/publications/housing/monitoring>

separate cross Government strategy on employment for people with learning disabilities will be published in early 2009, with its own impact assessment.

People as citizens

People with learning disabilities report that they are often the target of hate crime, that they are dependent on very limited and expensive public transport to get around, and that social isolation is one of the things they fear the most.

ANNEX C

Assumptions for Cost Calculations

Number of people known to services:

Based on latest research⁷⁶ the following numbers of adults with learning disabilities known to services has been used:

	2009/10	2010/11	2011/12
Best Estimate	201,000	213,920	226,840
High cost	201,000	217,320	233,640
Low cost	201,000	211,880	222,760

Recommendation 1: training in learning disability awareness

- All existing clinical staff⁷⁷ require training.
- Specially funded training will take place over three years after which any top up training will be incorporated into equalities CPD.
- 1/3 of staff will be trained in each year.
- New staff will enter with appropriate training.
- 2 hour session required, employing specialist lecturer (people with learning disabilities or family carer supported by liaison nurse or CPD trainer) costing £60.
- 15 staff trained per session.
- Opportunity costs of 0.5 hours (best estimate) to 2 hour (high cost) above normal CPD allowance.
- Staff costs based on PSSRU 2007 figures with increase of 2% above inflation per annum.
- Should trusts decide they need additional training, this could be provided by liaison nurses carrying out on the job training, therefore reducing backfill costs. Assumed opportunity costs reduced by 50% in best estimate and no reduction for high cost.

Recommendation 2: increase production of learning disability leaflet

- Set up costs already paid as leaflet exists.
- Costs per annum at 2009 prices is £7k for marketing and £5k for production⁷⁸.

Recommendation 3: web-based e-learning package

- Set up £35k.
- Running costs £4k per annum at 2009 prices⁷⁹.

Recommendation 4: confidential inquiry into premature deaths

⁷⁶ Emerson and Hatton 2008

⁷⁷ figures based on 30/09/2007 headcount

⁷⁸ *Getting it Right* working group

⁷⁹ Ibid.

- Costs are difficult to estimate as a similar CI has not been set up and carried out.
- Inquiry costs between £2m and £5m including the cost of the tender process. Best estimate is taken as £4m⁸⁰.
- £0.5m set up costs in year 1 and remainder split between years 2 and 3.

Recommendation 5: extend health action planning

Costs include:

- set up of HAPs for all people with learning disabilities known to services, maintenance of HAPs by social workers for PMLD cases and employing sufficient healthcare facilitators to meet requirements.

Setup:

- 80 PCTs provide good investment (based on the employment of a primary care facilitator) and 70 provide low investment⁸¹.
- In areas with good investment, between 40% (high cost) and 60% (low cost) – so take 50% as best estimate – of people with learning disabilities have a HAP.
- In areas with low investment, between 10% (high cost) and 30% (low cost) – so take 20% as best estimate – of people with learning disabilities have a HAP.
- Everyone known to services with a learning disability will have a HAP at the end of the 3rd year.
- Take up, by those who don't have a HAP, will be slow to start with so assumption is that 20% will get one in the first year, 40% of those still without will get one in the second year and the remainder will get one in the final year.
- Average cost of setting up a HAP is £40 based on Westminster PCT experience.
- Cost of set up is one off.

Maintenance for people with profound learning disabilities:

- Number of people with profound learning disabilities is 60% (high cost), 50% (best estimate), 40% of people with learning disabilities known to services.
- 65% of those with HAPs have profound learning disabilities until all have HAP.
- Time required for annual maintenance of HAP will be 3 hours (high), 2 hours (best) or 1 hour (low).
- Social worker salaries will increase by 2% above inflation.

Recommendation 6: DES on health checks; training and data collection

Costs for health checks for all people with learning disabilities known to services⁸²:

- GP time required in minutes is 50 (high), 25 (best) or 15 (low).
- Nurse time required in minutes is 90 (high), 50 (best) or 30 (low).
- Admin time required in minutes is 15 (high), 10 (best) or 5 (low).
- Staff salaries will increase by 2% above inflation.

Costs for training⁸³:

⁸⁰ Stoddart S & Stevenson E, unpublished, 'Business Case for a Confidential Inquiry into Premature Deaths in Patients with a Learning Disability' NHS National Patient Safety Agency, October 2008.

⁸¹ Stephan Brusch and Mark Bradely – Scoping Exercise of Health Facilitators 2008

⁸² Based in part on the 'Primary Care evaluation audit and research in learning disabilities (PEARL) study by the Welsh Centre for Learning Disabilities 2002

⁸³ Ibid.

- GP time required for IT training per GP surgery is 1 hour
- Nurse time required for IT training per GP surgery is 3 hours
- Staff salaries increase each year by 2% above inflation
- 8,400 GP surgeries in England
- 1/3 of GP surgeries will receive IT and attitude training each year
- Attitude training costs £250 per GP surgery which rises by 2% above inflation each year (since cost is largely labour)

Recommendation 7: establishment of acute hospital liaison and primary care facilitation posts

Acute hospital liaison:

- One liaison nurse per hospital trust (best estimate).
- One liaison nurse per trust for 50% of trusts and 2 for the remainder (high cost).
- One liaison nurse per 500,000 population (low cost)
 - Number of liaison nurses in post is 30.
 - Average cost of liaison nurse is £50k⁸⁴.
 - Staff costs increase at 2% above inflation.

Employment of healthcare facilitators:

- Number of facilitators required⁸⁵ is 1 per 150k of population (high cost), 1 per 250k of population (best estimate) or 1 per PCT (low cost).
- There are currently 80 facilitators already employed.
- Facilitators cost same as liaison nurses and salaries will increase by 2% above inflation.
- Build up of staff will take place over 3 years as follows: high cost (70%, 90%, 100%), best estimate (50%, 80%, 100%), low cost (33%, 67%, 100%).

Recommendation 8: public health observatory (PHO)

- Lower cost option of using virtual PHO, if similar to Drugs PHO, would cost about £160k per annum (this is not shown in the costings as it is not the preferred option and doesn't work out as lowest cost).
- Best estimate is using the obesity PHO model based at a PCT with costs estimated at £1.8m (high), £1.56m (best) or £350k (low).
- This cost would be one off, including the cost of set up of about £500k in year 1, with the remainder spread over years 2 and 3 (this is a cost to PCTs).

Recommendation 9: strengthen structure, role and accountability of partnership boards (PBs)⁸⁶

- (a) Set up regional programme boards: 9 boards required. 4 meetings of 4 hours required per year. 5 senior managers required for each board. Expenses for

⁸⁴ Based on Agenda for Change Band 7

⁸⁵ Based on experience of Staffordshire and Stoke-on-Trent PCTs

⁸⁶ Based on information provided by *Valuing People* regional leads

- each board member are estimated as £500 per annum. Staff costs increase at 2% above inflation. Costs split evenly between SHAs, PCTs, LAs and VPST⁸⁷.
- (b) Working with PCTs: 6 hours for each of 6 meetings per year attended by PCT manager. 4% of PCTs not attending at all so full additional cost required. 22% attending some of meetings (high cost 40%, best 50%, low cost 60%). Staff costs increase at 2% above inflation
- (c) to (g) Additional work of PBs require 0.4 FTE admin support per partnership board and one extra meeting per year. Staff costs increase at 2% above inflation.
- Additional meetings for PBs – high cost estimate assumes 2/3 PB require one extra meeting and 1/3 require 2, best estimate is that each requires one extra meeting, low cost estimate assumes 2/3 don't require an extra meeting and 1/3 requires an extra 1. (This a cost to LAs)
 - All meetings require 3 managers for 4 hours and each manager will incur £133 expense per meeting. (Cost is divided 82% to LA, 12% to PCT and 6% to SHA).

⁸⁷ Rachel Fyson and Liz Fox: *The Role and Effectiveness of Learning Disability Partnership Boards*, commissioned by Mencap and the Learning Disability Task Force from the University of Nottingham, 2008. *Speaking Up, How Well are Partnership Boards hearing the voices of people with learning difficulties and family carers?* Commissioned by the Valuing People Support Team January 2008

Annex D

Competition Assessment:

Do the recommendations directly limit the number or range of suppliers?

No.

Indirectly limit the number or range of suppliers?

No.

Limit the ability of suppliers to compete?

No.

Reduce suppliers' incentives to compete vigorously?

No.

Small Firms Impact Test:

In general we do not forecast that any of the recommendations will have any major impact on small firms.

Legal Aid:

It is not anticipated that recommendations will have any impact on legal aid.

Sustainable Development:

The recommendations take account of and support the five principles of sustainable development:

- living within environmental limits;
- ensuring a strong, health and just society;
- achieving a sustainable economy;
- promoting a good governance; and
- using sound science responsibly.

Carbon Assessment and Other Environment:

No impact has been identified.

Health Impact Assessment:

Recent research has shown that the health needs of people with learning disabilities have not been properly addressed by the NHS, most recently in the report *Healthcare*

for All which makes a number of recommendations covered in *Valuing People Now* and in this Impact Assessment. One of the high level objectives of *Valuing People Now* is to ‘improve the quality of healthcare for people with learning disabilities’. There will be no adverse effect on the health of people with learning disabilities as a result of the *Valuing People Now* Strategy being implemented.

Race Equality:

See attached Equality Impact Assessment.

Disability Equality:

See attached Equality Impact Assessment

Gender Equality:

See attached Equality Impact Assessment

Human Rights:

See attached Equality Impact Assessment

Rural Proofing:

Although there are no recommendations aimed specifically at benefitting people with learning disabilities living in rural settings, *Valuing People Now* recognises the importance of enabling people with learning disabilities and their carers in rural settings to access the same level of services and support as are available to people with learning disabilities in the rest of the country. We expect all people with learning disabilities to benefit from *Valuing People Now*, which seeks to improve healthcare and social care services for people with learning disabilities across the board.



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