Secretary of State Report on Disability Equality

Health and Care Services

DH INFORMATION READER BOX

Policy	Estates
HR/Workforce	Performance
Management	IM & T
Planning	Finance
Clinical	Partnership working

Document Purpose	For information
Gateway Reference:	10962
Title	Secretary of State for Health report on Disability Equality
Author	Department of Health
Publication date	01 Dec 2008
Target audience	
Circulation list	
Description	Secretary of State for Health report on progress made on disability equality in the health and care services sector.
Cross reference	DH Single Equality Scheme
Superseded documents	N/A
Action required	N/A
Timing	**By 01 Dec 2008**
Contact details	Lorraine I Thomas Department of Health Skipton House London SE1 6LH 020 7972 5036 http://www.dh.gov.uk/en/Managingyourorganisation/Equalityandhumanrights/index.htm
For recipient's use	

Contents

Foreword by the Secretary of State for Health

Since 2005, all public bodies have been under a duty to pay due regard to the need to promote equality of opportunity for disabled people.

Promoting equality for disabled people in the health and care sector means changing the culture and addressing barriers that result from lack of awareness about the causes and consequences of discrimination. This requires a huge effort and strong leadership to embed sustained good practice in the organisations that are responsible for developing policy, planning, commissioning and providing health and social care services. This report outlines action the Department is taking to ensure the various parts of the sector work more closely together and to identify and address barriers to progress.

Redressing problems that have built up over decades will take time. In some areas we still need to see a fundamental change in culture and attitudes. This is often simply about raising awareness of what promoting equality for disabled people means in practice. Small changes, for example to ensure that people with visual or hearing impairments know when they are called to appointments, or arranging evening care for someone whose needs change when they go back to work, make a significant difference.

Over the past three years the shift to planning and providing health and social care in ways that focus on outcomes for individual patients is paying dividends. We are driving change through better planning and commissioning based on the principles set out in *World Class Commissioning.* This autumn we completed consultation on a new *NHS Constitution* that will set out rights and responsibilities of patients, public and staff, reaffirming as a core principle the right to equal access to NHS services for all.

More people are now getting individual budgets so that they can choose what goes into their care packages and, from next year, we will be piloting individual budgets in personal healthcare. We are taking action to improve mainstream healthcare for people with learning disabilities and long-term mental health conditions.

We are investing in campaigns such as *Dignity in Care* and *Time to Change* to tackle abuse and disrespect for older people and people with mental health problems.

Across government, we are working to improve outcomes for disabled children and their families, and to support people to remain in and return to work. Within the Department of Health, we are taking steps to improve employment opportunities for disabled people.

This report affirms our commitment to improving equality for disabled people in health and social care, and to extending involvement and consultation in deciding what we should do and how we should do it. It provides a starting point to measure the progress we are committed to making.

Alan Johnson

Rt. Hon. Alan Johnson MP
Secretary of State for Health
December 2008

Executive Summary

The Department of Health (DH) is committed to equality. To ensure it remains an effective government champion for health and wellbeing for all, it will:

- **set national direction and priorities, supporting the delivery of health and social care, in ways that promote equality. It will also tackle health inequalities that result from disadvantage and damaging discrimination;**
- **take action to support people, maximising their potential by maintaining and promoting their health, wellbeing, independence, choice and control;**
- **help everyone who works for the Department deliver these goals, recognising the value of their differences in the contribution they make.**

1. When the general Disability Equality Duty was introduced, it marked a significant advance on the requirements previously set out in the Disability Discrimination Act 1995, as it requires all public bodies to have due regard to the need to promote equality of opportunity for disabled people. A number of specific duties have been introduced to help public bodies meet the requirements of the general duty. These include a requirement on the Secretary of State for Health to publish an overview of progress towards equality of opportunity for disabled people in his policy sector, and proposals for coordinating action to achieve further progress.

2. This report meets that requirement. It celebrates successes across the health and social care sector and acknowledges where we have more to do to live up to expectations. It highlights what has been done, or is in the process of being done and it sets out the progress we expect to make over the next period.

Scope

3. This report draws on the available evidence and case studies reflecting national, regional and local points of view to assess progress in meeting the requirements of the Disability Equality Duty and remaining areas where more needs to be done across the health and care sector.

4. We have sought to ensure the report covers as much of the extensive range of activity across the sector as possible. Inevitably a report of this sort will not provide a fully comprehensive picture. The report sets out:

- progress made since the publication of the Disability Equality Scheme which formed part of the Department's 2006 '*Single Equality Scheme*'[43]
- action following:
  - the Disability Rights Commission's report, '*Equal Treatment – Closing the Gap': A Formal Investigation into Physical Health Inequalities Experienced by People with Learning Disabilities and/or Mental Health Problems*'[19]
  - commitments made in the Government's "*Independent Living- A Cross-Government Strategy about Independent Living for Disabled People*'[26]
  - the Joint Committee on Human Rights' report on Learning Disabilities, '*A Life Like Any Other? Human Rights of Adults with Learning Disabilities*'[1]

  - consultation on '*Valuing People Now: From progress to Transformation- a Consultation on the next three years of Learning Disability Policy*'[55]
  - the report of the Inquiry chaired by Sir Jonathan Michael '*Healthcare for All: Independent Inquiry into Access to Healthcare for all People with Learning Disabilities*'[22]
- the changing regulatory environment for health and social care with the creation of the Care Quality Commission in April 2009; and
- sector-specific steps for building on the progress already made toward achieving disability equality.

5. The report explains how we are using Equality Impact Assessments locally and nationally to identify where policies need to be adapted to promote equality for disabled people; and how health and social care commissioners and providers are held to account.

6. Disabled people have been involved in setting the direction of this report, both formally (through staff or focus groups on 23 January 2008 and 29 October 2008) and informally, through discussions between August and October 2008.

Delivering personalised services

7. The Department's aims for health and adult social care are:

- **To promote better health and wellbeing for all –** this covers the Department's objectives to help people stay healthy and well, empower them to live independently, and tackle health inequalities;
- **To ensure better care for all** – this includes the Department's objectives to provide the best possible health and social care services, offering safe and effective care when and where people need help and empowering them in their choices; and
- **To ensure better value for all –** this incorporates the Department's objectives to deliver affordable, efficient and sustainable services, contributing to the wider economy and nation

8. Delivering these aims means developing policy and practice for health and care that supports personalised services. Services need to fit in with people's lives and focus on keeping them well and independent as much as on dealing with crisis situations. The strategic agreement between Government and key partner organisations, '*Putting People First: a shared vision and commitment for transformation of adult social care*'[39] set out the Government's expectations for change to promote a joined up support system focused on the health and wellbeing of local people.

9. The Government has also announced a Green Paper on the reform of the Care and Support system. The six month public engagement on the future of Care and Support, launched by the Prime Minister in May 2008 to establish the principles for the Green Paper, has been deliberately broad, involving both stakeholders and the public around the country. The Department has specifically aimed to involve and engage with key equality groups and their representative organisations. Where people have been unable to engage through the formal events, extra resource has been used to ensure that groups who are sometimes marginalised by a process of this sort have also been able to contribute their views.

10. The resulting Care and Support Green Paper, which will follow on from this engagement, will build upon the solid ground set out in the '*Putting People First*' concordat by putting forward options for future Care and Support that are fair and equitable to all.

11. Delivering personalised services means giving everyone who uses health and social care services – and their families – more choice about what care they get and the information they need to make choices. For disabled people, that may mean making adjustments in what services are available and how they are provided to ensure equality of access, as well as supporting them or their families to make choices. Disabled people who use health and care services should experience care that is linked effectively with the wider health and care network, focuses on individuals and allows each person to help plan and direct their own support.

The key issues and next steps

12. In this report, we summarise the ideas first described in '*Putting People First*'[39] which set out the direction for health and social care for the next decade and beyond. It committed the whole sector to working together towards a society that values the contribution that all citizens make. This report looks at what that means in practice, how people can best exercise choice and control in their lives and what they need if they are going to live as independently as possible.

'*Putting People First*'[39] has four main dimensions:

- universal services
- early intervention and prevention
- choice and control for people receiving services and their carers
- building social capital

13. This report explains how the Department, local health and social care commissioners and their partner organisations are working together to provide personalised services that meet the needs and aspirations of disabled people. It also sets out proposals for further progress to address ongoing problems identified in recent inquiries and reports.

Proposals for action

Breaking through the barrier of 'attitude'

14. Promoting equality for disabled people in the health and care sector means changing the culture and addressing barriers that result from lack of awareness about the causes and consequences of discrimination. This requires a huge effort and strong leadership to embed sustained good practice in the organisations that are responsible for developing policy, planning, commissioning and providing health and social care services. This report outlines action the Department is taking to ensure the various parts of the sector work more closely together and to identify and address barriers to progress.

Improving information

15. This report outlines how good information can make a significant difference in planning local services to meet the needs of disabled people and how doing so improves health and social care outcomes. Often, lack of consistent information about how health and social care services impact on individuals with different needs has hampered the pace of progress.

16. The Department has set up an Equality Monitoring Group bringing together experts from across policy, information, performance and delivery organisations. This has helped bring a much more focused approach to improving, collating and analysing data on equality. The Group will take forward recommendations from the cross-government group that is considering how best to record information on disability in the public sector. It is also leading work at national level to look at whether the key indicators for measuring NHS performance show significantly different outcomes for people in different equality strands. The analysis will cover outcomes for disabled people where data is available and recommend action to fill gaps where it is not.

17. Over time, this will help track outcomes for disabled people compared to other patients and service users and begin to build a much richer picture of progress towards achieving disability equality in the health and social care sector , addressing some of the criticisms made in *'Up to the Mark?'*[53].

Consulting and involving disabled people

18. Over the past few years, the health and social care sector has been getting better at involving users in the development, planning and delivery of services. While nationally, there are many examples of good practice more needs to be done to consult and involve disabled people.

19. *'World Class Commissioning'*[58], the *'NHS Operating Framework for 2008-09'*[47] and the NHS Next Stage Review reflect the shift of involvement to the forefront of the policy agenda. Section 242 of the NHS Act 2006 places a duty on NHS bodies to make arrangements to involve service users on certain plans, proposals and decisions in relation to health services for which they are responsible. *'Real Involvement: working with people to improve health services'*[40] provides detailed guidance and best practice for the NHS on what is required, why effective involvement is important and how to involve the right people. The guidance includes specific sections on involving people who require different ways of communicating.

20. An increasing number of disabled people are becoming involved in national consultations and subsequently through programme development and policy governance. Disabled people are acting as key members of the Learning Disability Programme Board and local learning disability partnership boards. They also act as health trainers, and in ad hoc activities that bring together disabled stakeholders, facilitated through third sector organisations. The Department is committed to further improving arrangements for systematic involvement and consultation with disabled people and other equality stakeholders; we are commissioning an independent review to help identify what further changes we need.

Setting targets that are clear, consistent and ambitious

21. This report identifies a number of Public Service Agreement (PSA) and Departmental Strategic Objectives (DSO) targets led by the Department of Health that should improve the life chances of disabled people.

22. There has also been good progress in identifying changes that will help support better outcomes for disabled people in health and social care. The Local Government National Indicator Set has a number of disability-focused health and wellbeing indicators that can be used locally to help plan and deliver services across the public sector. Over time, increasing use of this kind of information at national and local levels will help the NHS and social care services monitor progress and decide on local priorities for changing and developing services.

23. Across the health and care sector, we track progress through reports against key indicators set out in the NHS Operating Framework 2007/08 and independent assessments undertaken by the Healthcare Commission, the Commission for Social Care Inspection and the Mental Health Act Commission. From next year, this role will be picked up by the new Care Quality Commission.

24. Recent assessments by the Healthcare Commission have been disappointing. The Department is taking steps to strengthen performance on disability equality by building on existing targets, specifically to improve access to general health services for disabled people. The NHS Chief Executive has asked all strategic health authorities to report on action they are taking to improve services for disabled people and this will be pursued in the context of implementing the NHS Operating Framework for 2009/10.

25. Mencap's report *'Death by Indifference'*[15] in March 2007 highlighted problems with health services for people with learning disabilities. The subsequent report of the Independent Inquiry into access to healthcare for people with learning disabilities, chaired by Sir Jonathan Michael highlighted widespread underperformance alongside much good practice. We will be formally responding to the key recommendations in that report when we publish our '*Valuing People Now*'[55] strategy.

Delivering services in partnership

26. Partnership working across organisations responsible for commissioning and providing health and social care is important in planning packages of care to meet individual needs. It is also important in linking different aspects of prevention and health promotion activities to support better outcomes for all disabled people.

27. *'High Quality Care for All – the Next Stage Review final report'*[23] gives the NHS a clearer focus on promoting health and wellbeing and preventing ill health, and not just detecting illness and curing it. Personal budgets, care plans for people with multiple and long-term conditions and integrated care will be key components.

28. Reconfiguration of Primary Care Trusts in 2006 enabled better alignment of health and adult social care services. The 2006 Local Government White Paper *'The Local Government and Public Involvement in Health Act 2007'*[46] and 2007 Local Government and Involvement in Public Health Act put more emphasis on partnership working, joint performance assessment and national level cooperation across government and the NHS. In particular, the Act requires primary care trusts and local authorities to produce Joint Strategic Needs Assessment.

29. Joint Strategic Needs Assessment introduced in 2008 ensures a strong requirement on primary care trusts and local authorities to jointly assess the needs of their local population. These assessments provide a stronger evidence base for local decisions on what needs to be included in Local Area Agreements to improve outcomes for disabled people. NHS and local authority commissioners are now in a stronger position to specify outcomes that encourage local innovation and help providers develop services that respond to local needs.

30. The *'Commissioning Framework for Health and Wellbeing'*[11] sets out strategic aims to change patterns of service commissioning in ways that will help achieve good outcomes for individuals through shifts towards services and interventions that:

- are personal, sensitive to individual need and that maintain independence and dignity
- promote health and wellbeing
- promote inclusion and tackle health inequalities

The whole health and care sector has a role in supporting delivery of wider Government objectives led by other Departments, that will help address disadvantage, social exclusion, and help support children's health and wellbeing.

Putting the evidence of what works into practice

31. As part of the Government's *Independent Living Strategy*[26] the Department committed to taking action to raise awareness of disability across the health and care sector. This will include a comprehensive programme of work to create and refresh specific disability equality guidance.

32. The Department is currently working with six strategic health authorities and 36 NHS trusts delivering the *Pacesetters programme*[35]. Organisations involved in the programme focus on specific projects to improve equality for patients, service users and staff. The objective is to:

- identify what needs to be done to reduce health inequalities for patients and service users
- ensure patient and user involvement in the design and delivery of services
- deliver working environments that are fair and free of discrimination

33. The programme uses evidence from local, national and international best practice and research and works with each organisation to identify what changes are likely to make a difference, what action to take and how to measure progress. Regular evaluation of local projects means good practice can be captured and shared with other organisations. The next wave of the programme is themed around improving outcomes for disabled people in the areas of cancer, diabetes and cardio-vascular disease.

34. More generally, the Department is taking action to extend and improve the use of Equality Impact Assessment as an integral part of good policy design and implementation at national, regional and local level. Assessments are being used at local level in informing decisions about what should go into Local Area Agreements and in the work of Overview and Scrutiny Committees.

Building capacity and supporting independent living

35. This report looks at how resources are being used in new ways, for example through individual budgets to support good outcomes and extend opportunities for disabled people.

36. Sustained action to improve outcomes for disabled people is not just about finances, though. Neither is it just about awareness. We need to build the capacity and capability of our workforce. This means not just promoting equality for the disabled people who use health and social care services, but also ensuring that disabled people have an equal opportunity to progress if they choose to have careers in the health and care sector.

37. Every NHS organisation is using the Electronic Staff Record. This will ensure the same information is recorded about every employee across the whole of the health sector. So, for the first time, we will have consistent disability equality monitoring right across the NHS workforce.

38. We have seen a very welcome increase in the number of disabled people working in public, independent and third sector organisations. The Government response to Dame Carol Black's report on the health of Britain's working age population *Improving health and work: changing lives*[25] sets out action that we are taking in partnership with others that includes improving support for people with or without disability to remain in and return to work, and the commissioning of a review of the health and wellbeing of the NHS workforce.

39. This report also sets out a range of activity across the health and care sector in partnership with third and independent sector organisations to extend and embed action that supports independent living for disabled people. This includes improving the quality of information and advice to help people understand how to get the best out of the services that are available and specific programmes to support:

- prevention, early intervention and self-care
- carers, volunteering and third sector initiatives
- housing and other adaptations to enable people to live in their own homes

40. This report outlines a number of proposals for further action. Starting with a seminar early in 2009, the Department will involve disabled people in helping track progress on these initiatives and in defining what other action we should prioritise over the next three years. Formal governance and accountability for progress will be assured through the Department's Equality and Human Rights Assurance Group which is accountable through the Corporate Management Board.

Conclusions

41. Equality of access to high quality health and care services is central to the lives of many disabled adults, children and their carers. This report provides an overview of progress and discusses ongoing action in the health and social care sector to improve outcomes for disabled people. It identifies sector responsibilities for coordinated action between national, regional and local services, as well as partnership working with other Government Departments.

42. This first report represents a starting point. It sets out where things stand at the end of 2008. Many of the initiatives discussed require longer-term action and new initiatives are being developed all the time. We welcome comments, these should be sent to equalityhumanrights@dh.gsi.gov.uk. We will report updates on the Department's website. http://www.dh.gov.uk/en/Managingyourorganisation/Equalityandhumanrights/index.htm.

Summary of key initiatives to support disability equality in health and social care

Improving access and integrating care for disabled people

Comprehensive annual health checks for people with learning disabilities.

Increased resources to improve disability awareness in primary care services.

Further training of GPs and GP practice staff, with service levels at the first point of contact being a major focus.

Extra £7 million allocated to fund Well-Being Nurses to perform health care checks and support health living groups for people with severe mental illness.

Easier access to Community Equipment provided by a choice of accredited retailers.

An action plan will be developed to respond to recommendations made by John Bercow MP, following his review of services for children and young people with speech, language and communications needs.

Accessible information on end of life care being provided to people with learning disabilities through the Books Beyond Words Project.

'*Better Care, Better Lives*' A new national strategy for children's palliative care is currently being formulated

Working with Ministry of Justice to test provision of community based treatment

Supporting independent living

SHIFT, a Department of Health funded programme is planning to fund a 'Stigma Watch' website. It will allow people to give feedback regarding media coverage.

All individuals eligible for publicly funded adult social care will have a clear up-front allocation of funding.

Introduction of Individual Budgets for disabled children, this will ensure that families are placed at the centre of the care planning process.

'Work Focused Health Related Assessments' will follow on from the Department for Work and Pensions 'Work Capability Assessments'.

Pilots for Personal Health Budgets.

Employment advisers will be embedded within Improving Access to Psychological Therapies from early 2009 and also be placed in GP surgeries as part of the Pathways Advisory Service. 'Fit for Work' service pilots will provide case-managed multidisciplinary support; various models will be tested.

A new electronic 'fit note' will be introduced across Britain in 2009. The 'fit note' will replace the current medical certificate. The revised medical certificate will focus on what people can do rather than what they cannot. This is to help GPs adapt the advice they give to help people stay in or return to work.

A National Education Programme for GPs will be rolled out across Britain in 2009, which will improve GP's knowledge, skills and confidence when dealing with health and work issues and enable them to adapt advice they give to help people get in or stay in the workforce.

Health, Work and Well-being Coordinators will be appointed and be based in the English regions from Summer 2009. The Coordinators will stimulate action on health, work and well-being issues in their areas.

A National Centre for Working Age Health and Well-being will be established in late 2009. It will identify evidence gaps and encourage research to close those gaps.

The National Strategy for Mental Health and Employment will be published in Spring 2009. This will aim to bring employment and health services closer together.

The Access to Work programme will be increased and the effectiveness improved.

Developing capacity and capability in delivery of health and care services

A review of the health and well-being of the NHS workforce will be commissioned.

Work with Skills for Care to develop tools to support learning disability awareness amongst staff working with people with learning disabilities – new knowledge sets by March 2009.

NHS Employers working with the General Medical Council and Nursing and Midwifery Council developing fitness for practice guidance and access to training.

National Framework for Disability Equality and Etiquette Learning for health and social care services is in place.

Launch of 'Treat me right' leaflet on how to work with people with learning disabilities.

The NHS Change Programme (Pacesetter Wave 2) is developing ways to help people with mental health and learning disabilities into paid employment.

Improving policy design and implementation

Disaggregation by equality strands of the NHS Vital Signs indicators, the key indicators of performance in the NHS.

Improving involvement and consultation with disabled people.

Development of guidance and tools to support health and social care professionals.

Equality Impact Assessment of all Department of Health HR policies involve staff groups.

Establishment of Equality and Human Rights Assurance Group.

Launch of cross-Department of Health wellbeing strategy and mental health wellbeing guidance.

Launch of flexible working and other training and support for reasonable adjustment in the case of sickness absence.

Range of guidance on disability to support World Class Commissioning and Joint Strategic Needs Assessment.

Implementation of recommendations from Informatics Review will improve accessibility of information on policy design and implementation.

Chapter 1: The Policy Sector

This chapter sets out the context for this report and explains how the Secretary of State for Health's responsibilities are exercised through the health and social care system and how we are working across Government to achieve disability equality

The background to this report

1.1 Secretaries of State are required to publish reports setting out progress made towards disability equality across key policy sectors. They must also outline their proposals for making further progress in the future. Reports are published every three years and are open to scrutiny by Parliament.

1.2 The Secretary of State reports are a unique aspect of the Disability Equality Duty. They are the result of collaboration across Government departments and are comprehensive in their scope.

1.3 The Department of Health Single Equality Scheme focuses on specific actions within the Department but this report looks more widely. It highlights disabled people's experience of health and social care services. It focuses on action being taken to improve personalised services for disabled people and to promote disability equality throughout the sector. It acknowledges where more needs to be done. It also shows where barriers to integrated care have been successfully removed and how organisations are actively working towards equality of access.

Commitment and approach to the disability equality duty

1.4 The Department of Health subscribes to the social model of disability, defining disability as the disadvantage experienced by an individual as a result of barriers (attitudinal, physical etc) that impact on people with impairments and/or ill health.

1.5 We are committed to disability equality and strive to be an effective government champion for health and wellbeing for all.

The wider perspective on reporting on disabilities

1.6 We produce our Disability Equality Scheme as an integral part of a Single Equality Scheme (SES). The Department of Health Scheme sets out our policy and stewardship role for health and adult social care. The organisations that make up the NHS are, however, have a range of accountability and governance arrangements. They have a responsibility to produce and make available their own Disability Equality Schemes.

1.7 This report is underpinned by the Department of Health's Single Equality Scheme, as well as the schemes of organisations within the sector. The Department's 2006 Single Equality Scheme, in particular, is the main reference point for this report.

1.8 More widely, we are committed to the principles set out in the '*UN Convention on the Rights of Persons with Disabilities*'[10] and its Optional Protocol, adopted by the United Nations General Assembly in December 2006, and opened for signature in March 2007. The Convention aims to secure for the estimated 650 million disabled people across the world the same human rights enjoyed by non-disabled people.

1.9 Article 1 specifically states that "persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others". The UK Government is committed to ratifying the Convention by the end of 2008.

The policy sector

1.10 The policy sector as defined by this report covers the health and adult social care system in England for which the Department of Health is responsible. The Department of Health develops policy and provides stewardship. It:

- gives direction to the NHS, adult social care and public health and has general responsibility for standards of health care in the country
- sets the strategic framework for adult social care and influences local authority spend on social care
- directs the promotion and protection of the public's health, taking the lead on issues such as environmental hazards to health, infectious diseases, health promotion and education, the safety of medicines and ethical issues.

Responsibility for commissioning and providing health and social care services

1.11 The Department of Health does not directly deliver healthcare or social care services to the public. This is done by a wide range of organisations and delivery partners. Each part of the health and social care system has a particular role and responsibilities which contribute to delivering better health and wellbeing, better care and better value.

1.12 We also work through specialist bodies accountable to the Department (or to Parliament) but operating at arm's length from Government. These include regulators focusing on particular areas such as improving standards or supporting local services. These 24 Arms Length Bodies (ALBs) produce their own disability equality schemes (or single equality schemes), monitoring their workforce and undertaking equality impact assessments.

Arms Length Bodies

AC Appointments Commission

AERC Alcohol Education & Research Council

CHRE Council for Healthcare Regulatory Excellence

CPPIH Commission for Patient & Public Involvement in Health

CSCI Commission for Social Care Inspection

CQC Care Quality Commission

GSCC General Social Care Council

HC Healthcare Commission

HFEA Human Fertilisation & Embryology Authority

HPA Health Protection Agency

HSCIC Health & Social Care Information Centre

HTA Human Tissue Authority

MHAC Mental Health Act Commission

MHRA Medicines & Healthcare Products Regulatory Agency

Monitor Monitor

NHS BSA NHS Business Services Authority

NHS BT NHS Blood & Transplant

NHSi NHS Institute

NHSLA NHS Litigation Authority

NHS PASA NHS Purchasing & Supply Agency

NHS P NHS Professionals

NIBSC National Institute for Biological Standards & Control

NICE National Institute for Health & Clinical Excellence

NPSA National Patient Safety Agency

Arms Length Bodies

NTA National Treatment Agency for Substance Misuse

PMETB Postgraduate Medical Education & Training Board

1.13 We work with the professional organisations forming the Academy of Medical Royal Colleges, and with Royal College of Nursing, Royal college of Midwives and a range of other professional organisations including those for Allied Health Professionals, dentists, pharmacist, optometrists and social care professionals. We also work with the professional regulatory bodies, such as the General Medical Council and Nursing and Midwifery Council that are responsible for professional standards and registration of key healthcare and social care professionals. All these organisations are also employers in their own right. These organisations produce their own disability equality schemes (or single equality schemes) and monitor their membership.

Royal Colleges

RCOA The Royal College of Anaesthetists (UK)

RCN Royal College of Nursing

RCGP The Royal College of GPs

RCOG The Royal College of Obstetricians and Gynaecologists

RCOPHTH The Royal College of Ophthalmologists

RCPCH The Royal College of Paediatrics and Child Heath

RCPATH The Royal College of Pathologists

RCPLONDON The Royal College of Physicians of London

RCPSYCH The Royal College of Psychiatrists

RCR The Royal College of Radiologists

RCS The Royal College of Surgeons of England

1.14 Ten Strategic Health Authorities (SHAs) provide the regional headquarters of the NHS, working with eight Government Offices for the Regions to improve the health of the population. Strategic Health Authorities have three main functions:

- providing strategic leadership;
- organisational and workforce development; and
- ensuring local systems operate effectively and deliver improved performance

1.15 Government Offices are responsible for co-ordinating central Government's relationship with each region. Working closely with Strategic Health Authorities, their responsiblities include negotiating improvement targets in local area agreements and coordinating action to respond to underperformance.

1.16 At local level, Primary Care Trusts (PCTs) and Local Authorities (LAs) are responsible for securing the provision of health and social services for their local populations. As commissioners of services, they are arguably the most powerful levers we have to promote disability equality and reduce health inequalities. The three main functions of a primary care trust are:

- engaging with its local population to improve health and wellbeing
- commissioning a comprehensive and equitable range of high quality, responsive and efficient services, within allocated resources, across all service sectors; and
- directly providing high-quality responsive and efficient services where this gives best-value.

1.17 Since 2004 those NHS Trusts considered to have been performing with outstanding efficiency have been able to apply to Monitor for authorisation as NHS Foundation Trusts. Those organisations which have gained

Foundation Trust status have a greater degree of autonomy from the Department of Health and are not subject to performance management by Strategic Health Authorities.

1.18 NHS Trusts are commissioned by Primary Care Trusts (PCTs) to provide a range of services, including hospital based care, mental health and ambulance services, which meet the expected health needs of the local populations. While individual services are commissioned by Primary Care Trusts, NHS Trusts (ie those that are not yet Foundation Trusts) are performance managed by Strategic Health Authorities.

1.19 Primary Care Trusts also commission or provide a range of community health service, such as district nursing and health visiting services and a range of services provided by Allied Health Professionals. Many of these services have a specific focus on meeting the needs of people with disabilities. Primary Care Trusts also commission primary care services, including GP services, dental services, community pharmacy services and NHS sight tests. Primary care and community health services are responsible for around 90% of patient contact with the NHS.

1.20 Local government is vital to meeting our main public health and social care outcomes. The NHS and local government need to work in close partnership to improve the progress of independent living for disabled people and to deliver effective adult social care. This is supported by joint responsibilities set out in the Local Government and NHS Acts.

1.21 Both Primary Care Trusts and local authorities commission a range of health and social care services from third sector and independent sector providers.

Social Care

1.22 Social Care funding comes from a combination of central government grants, council tax revenues and user charges. Some £2 billion is raised through user charges, which currently accounts for around 15% of gross expenditure on adult social care. Individual councils set their budgets for all their areas of responsibility, including social care.

1.23 Responsibility for social care for children lies with the Department for Children, Schools and Families (DSCF). The Department of Health is responsible for child health services.

Responsibilities for Policy and Delivery

1.24 The roles of policy developers and deliverers are set out in the Department of Health Strategic Framework[47]. The framework identifies the key principles, which support collaborative working, strong communication and clear accountability between policy and delivery. These principles are:

- deliverers inform policy development and decision-making
- outcomes and targets are agreed with deliverers before publication
- policy rationale is understood and championed by both
- deliverers are empowered to get on with delivery, held to account by monitoring, audit, and inspection
- strong two-way communication is vital, with deliverers reporting back regularly to policy on the achievement of outcomes.

Key Measures

Implementation at a local level

"Trusts need guidance on the scale of the work necessary so that resources are committed appropriately".

Extract of comments from disability stakeholder event – January 2008

1.25 An important step in the drive for greater compliance with equality duties has been the establishment of the Care Quality Commission. The commission brings together the expertise of the Healthcare Commission, the Commission for Social Care Inspection and the Mental Health Act Commission. The new arrangements will ensure a more consistent approach to regulation at a time when services are increasingly crossing traditional health and social care boundaries. The Care Quality Commission will actively pursue the commitment of the Equalities and Human Rights Commission to work with regulatory agencies to coordinate approaches.

1.26 The Care Quality Commission will set out how it will engage with and promote awareness among service users, and report on this annually. It will also reduce the burden of inspection on the frontline, reducing the level of duplication and bureaucracy faced by hospitals and care homes, while creating a level playing field across the public and private sectors.

Leadership and accountability

1.27 The Secretary of State for Health is responsible for providing leadership and accountability for the diverse system of health and social care that is delivered through many arms of the sector. As champion for health and wellbeing, the Secretary of State for Health discharges his responsibilities through the Department of Health and its arms length bodies, for delivery by local NHS and social care services. These responsibilities are set out in:

- Public Service Agreements
- Departmental Strategic Objectives
- Department of Health Strategic Framework
- NHS Operating Framework

Policy domains

1.28 Department of Health policies are driven by its three strategic objectives: better health, better care and better value for all.

1.29 These objectives reflect government Public Service Agreement targets and feed into NHS and local government objectives. They are measured through NHS Vital Signs and the Local Government National Indicator Set.

1.30 We pay particular attention to better health and care reaching all groups, taking action to reduce inequalities and the impact of discrimination on health outcomes.

Our aims in each area are:

Better health and wellbeing for all:

- securing and improving every citizen's overall health, life-expectancy and emotional well-being, irrespective of their background and circumstances
- improving citizens' quality of life – helping people to live healthier, more independent, disease-free lives
- helping the most vulnerable achieve their aspirations, building a fairer society.

Better care for all:

- improving safety, cleanliness, and delivery of optimum care

- making services more personal – more convenient, responsive and designed around the service user
- improving the experience for patients, carers, and service users – treating every person with dignity and respect and giving them more control.

Better value for all:

- ensuring an effective system that is productive and efficient, providing best value for money for the taxpayer
- securing the long-term sustainability of health and social care for this and future generations.

1.31 The structure of this report reflects these objectives and the priorities identified by disabled people and disability stakeholders. The following chapters cover better access to and integration of care and removing barriers to independent living.

Department of Health's contribution to Public Service Agreement delivery programmes

1.32 While shaping policy to our own priorities, we are committed to working with our partners at Cabinet Committee level on the Public Service Agreement programme boards and across all strands of sector delivery at regional, local, community and even neighbourhood level.

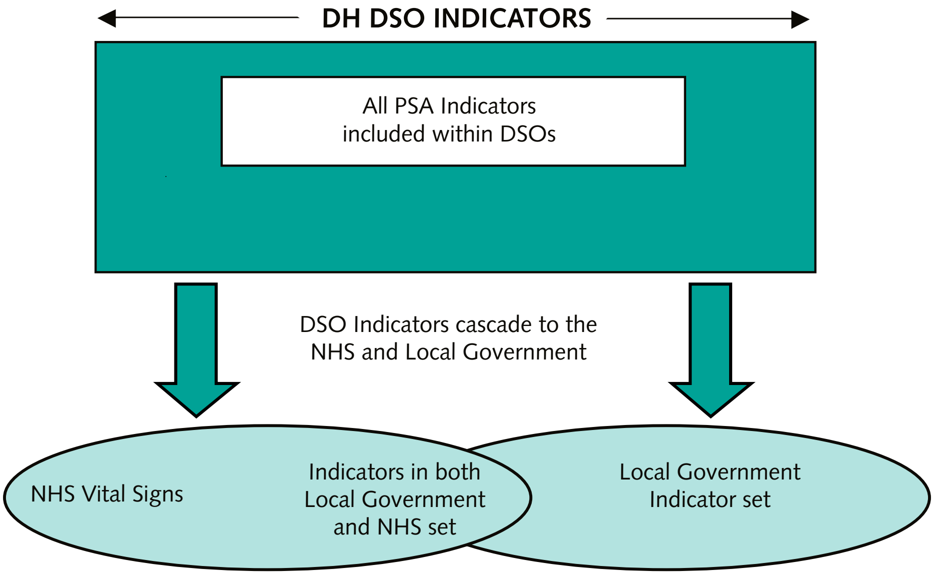
1.33 The following diagram shows how our priorities at national level are reflected at local level. Health and wellbeing indicators within the National Indicator Set reflect a high proportion of the NHS 'Vital Signs'.

Other PSAs to which Department of Health contributes

1.34 We also contribute to the delivery of cross-Government priorities through Public Service Agreement delivery agreements:

Maximising employment for all (PSA Delivery Agreement 8):

- Increasing overall employment rate
- Reducing the gap
- Reducing the number on out of work benefits
- Increasing retention in work



Improve the health and wellbeing of children and young people (PSA Delivery Agreement 12):

- Prevalence of breastfeeding at 6–8 weeks
- Levels of childhood obesity
- Emotional health and wellbeing, and child and adolescent mental heath services (CAMHS)
- Parents' experience of services for disabled children and the 'core offer'

Address the disadvantage that individuals experience because of their gender, race, disability, age, sexual orientation, religion or belief (PSA Delivery Agreement 15):

Increase participation in public life

- Working with partners
- Involving local service users

Reduce discrimination in employment

- Engaging with employers on the need to diversify workplaces
- Removing barriers to employment
- Public sector equality duties

Reduce unfair treatment at work, college or school, and when using health services and public transport

- Maximising the effects of strengthened legislative framework
- Inspecting performance
- Embedding dignity and respect in the health service
- Ensuring dignity and respect in schools and colleges
- Gender gap in hourly pay
- Level of choice, control and flexibility to enable independent living
- Participation in public life by women, ethnic minorities, disabled people and young people
- Discrimination in employment
- Fairness of treatment by services

Increase the proportion of socially excluded adults in settled accommodation and employment, education or training (PSA Delivery Agreement 16):

- Proportion of socially excluded adults in employment, education or training
- Adults in contact with secondary mental health services
- Adults with learning disabilities

Department of Health representation on shared areas of responsibility

1.35 We are committed to helping the successful delivery of these targets and the Department of Health is represented on the cross-departmental Public Service Agreement programme boards for PSA15 and PSA16.

Coordinated Public Service Agreement work programmes and supporting arrangements

1.36 Partnership working is achieved at local level through Local Strategic Partnerships. Every Primary Care Trust (PCT) is involved in a Local Strategic Partnership, driving the delivery of our Public Service Agreements at local level.

1.37 If we are going to achieve common outcomes, action at national, regional and local level must be coordinated. We have therefore established the process of Joint Strategic Needs Assessment (JSNA). It provides information to help local authorities and Primary Care Trusts understand what issues should be priortised in local area agreements. This includes understanding and taking account of how current patterns of service impact on disabled people and what changes are needed to improve outcomes.

Most relevant measures

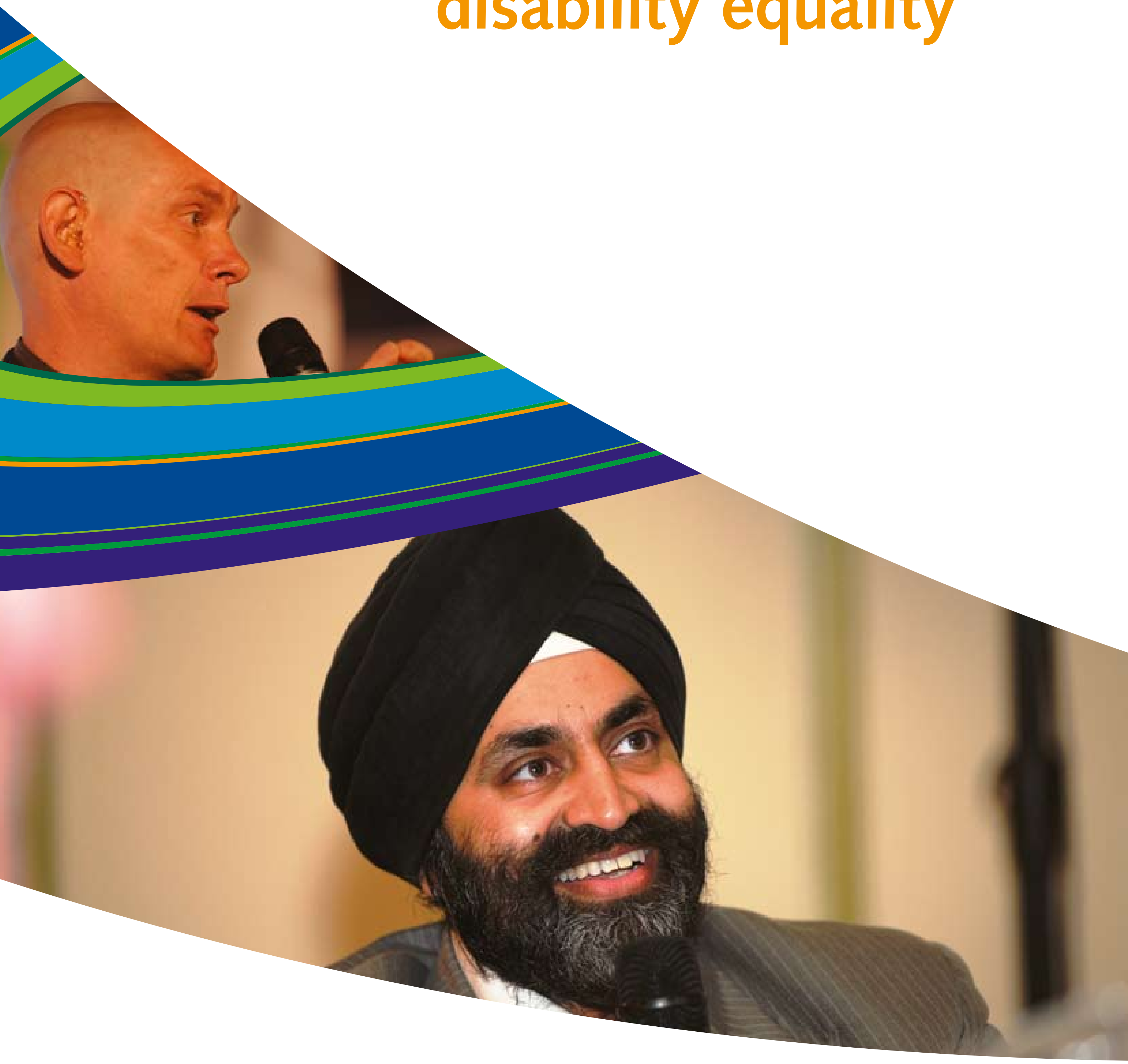
1.38 Throughout this report we have identified the key or most relevant measures. These will be listed later on in the report in Chapter 7.

Conclusions

- The health and care services policy sector is made up of a wide range of organisations each with its own governance and accountability arrangements and responsibility for disability equality;
- Although the wider sector is not under the direct control of the Department of Health, we should work in partnership with local NHS services, local government, third sector and independent sector organisations, professional organisations, groups representing service users and carers, and regulatory bodies to increase compliance with the requirement for a disability equality scheme;
- The Department of Health is represented on the PSA15 and PSA16 Programme Boards – this supports partnership with other Government departments and with wider partners to improve services and outcomes for disabled people;
- There is scope for Department of Health officials to develop better cross Government partnerships to promote these improvements, alongside continued partnership with the NHS, local government and other sectors;
- Joint Strategic Needs Assessment (JSNA) will support improved outcomes and reductions in health inequalities. This partnership duty involves a range of statutory and non-statutory partners which will inform and improve commissioning of wellbeing services;
- There is good work underway across the sector but this is not always communicated. Better communication of equality and human rights innovations will support local improvement action.

The following Chapter describes how we are building the right environment for disability equality in the sector.

Chapter 2: Setting the environment for disability equality



This Chapter describes:

- **Progress in the sector and why there is a case for further action**
- **Changes in the culture of policy making in the Department of Health**
- **Equality impact assessment of policies at national level**
- **Leadership and governance of disability equality and equality generally**
- **How we are involving disabled people in the sector**

The case for change

2.1 The health and care services sector has achieved improvements in recognising the needs of disabled people and in securing better outcomes. But there is still a long way to go to achieve the aim of better health and wellbeing and better care for all disabled people. Lasting change will not happen overnight in a sector which spans several hundred organisations and with some 1.3 million employees. It needs to be planned, resourced and managed with care. The first step is to recognise and build on the good progress that has already been made and address underperformance where they are identified.

2.2 The sector response to the Disability Equality Duty was reviewed by the then Disability Rights Commission in 2006. The Commission highlighted scope for improvement across the sector in three reports:

- *'Up to the Mark: How have Government Departments responded to the new Disability Equality Duty?'*[52]
- *'The Strategic Health Authorities and the Disability Equality Duty'*[48]
- *'Overview of Primary Care Trust Disability Equality Scheme Assessments by the Disability Rights Commission'*[33]

2.3 The following reports have helped inform how the sector takes forward action to achieve and sustain disability equality. The case for fundamental change is clear.

'Equal Treatment: Closing the Gap'[19], Disability Rights Commission

2.4 *'Equal treatment: closing the gap'*[19] reported on the formal investigation into physical health inequalities experienced by people with learning disabilities and/or people with mental health conditions. The Disability Rights Commission undertook their investigation because significant international research evidence showed people with learning disabilities and/or mental health conditions are more likely to die young and to live with potentially preventable physical health problems. This understanding has informed changes in NHS policy and practice to help 'close the gap' in physical health inequalities. Chapter 3 of this report outlines progress made in addressing these inequalities.

'Healthcare for all'[22] report of the Independent inquiry

2.5 In 2007 the then Secretary of State invited Sir Jonathan Michael to chair an independent inquiry into access to healthcare for people with learning disabilities. This inquiry was in response to Mencap's report, *'Death by Indifference'*[15], which examined the cases of six people with learning disabilities who died while under the care of the NHS. The independent inquiry advised on the national and local action needed to effect change and prevent such cases happening elsewhere.

2.6 The summarised recommendations from the Inquiry were:

- Those with responsibility for the provision and regulation of undergraduate and postgraduate clinical training must ensure that curricula include mandatory training in learning disabilities.
- All health care organisations to collect information that allows people with learning disability to be identified and their pathways of care tracked.
- Family and other carers should be involved as a matter of course as partners in the provision of treatment and care, and reasonable adjustments to be made support carers to do this effectively.
- Primary care trusts should identify and assess the needs of people with learning disabilities and their carers as part of their Joint Strategic Needs Assessment.
- The Department of Health to raise awareness, promote sustainable good practice in local assessment, management and evaluation of services for learning disabled people through the establishment of a Public Health Observatory.
- The Department of Health to amend Core Standards for Better Health, to include an explicit reference to the requirement to make ‘reasonable adjustments’ and the framework that is planned to replace these to also include a specific reference to this requirement.
- Inspectors and regulators of the health service should develop and extend their monitoring of the standard of general health services provided for people with learning disabilities. Healthcare regulators and inspectors should strengthen their partnership working.
- The Department should direct Primary Care Trusts to commission regular health checks provided by GP practices and improve data, communication and cross-boundary partnership working to improve the overall quality of health care for people with learning disabilities.
- All Trust Boards should ensure that the views and interests of people with learning disabilities and their carers are included.
- All Trust Boards to provide advocacy for all those who need it, and arrangements to secure effective representation from all client groups including people with learning disabilities.

2.7 The Department’s response will be published in the white paper following consultation on ‘*Valuing People Now*’[54].

Audit of inpatient learning disability services Healthcare Commission

2.8 In January 2007, the Healthcare Commission audited services for people with learning disabilities provided by the NHS and independent healthcare organisations. It found that most services were providing basic standards of care but that there were wide variations in standards within and between organisations. In particular, the quality of care for people with learning disabilities was identified as an area of concern. Chapter 4 provides an outline of the progress made.

‘A Life Like any other’[1] Joint Commission for Human Rights

2.9 The Joint Committee on Human Rights published its report *‘A Life like Any Other? Human Rights of Adults with Learning Disabilities’*[1] in March 2008. The Government published its response in April 2008. The Joint Committee’s report highlighted the importance of a human rights based approach for people with learning disabilities. The ‘*Valuing People Now’*[54] strategy reflects this approach: it reaffirms human rights as one of the four guiding principles which underpin the whole strategy.

2.10 In its initial response, the Government undertook to provide the Committee with a further response following its consultation on *‘Valuing People Now’*[54]. This will be published in due course.

‘Working for a Healthier Tomorrow’[57] Dame Carol Black’s report

2.11 Commissioned jointly by the Department for Work and Pensions and the Department of Health in 2007, the report provides a baseline assessment of the health of the working age population in Britain. This review made recommendations to Government and stakeholders on ways to improve working age health and help more people to enter and stay in work. Chapter 4 provides an outline of our co-ordinated response.

Review of speech, language and communication needs[45] John Bercow MP

2.12 John Bercow MP undertook a review of services for children and young people with speech, language and communication needs. His report recommended the setting up of a Communication Council to monitor and support the implementation of the Review’s recommendations. The remit of the Council would include:

- promoting the importance of speech, language and communication;
- monitoring national progress in improving services and outcomes for children and young people with all forms of speech language and communication needs;
- recommending improvements to Ministers; and
- identifying and sharing effective practice.

2.13 The report also recommended the appointment of a Communications Champion to promote change and improvement.

Our considerations in determining progress:

How are we ensuring the right environment exists for delivering disability equality?

How is the health and care sector leadership working toward disability equality and what governance arrangements are in place?

How are we, as both policy makers and delivery agents, involving disabled people in decision-making processes?

How are we ensuring policy-makers take due regard of disability equality when developing policies for the health and care sector?

How are we assuring ourselves that local and operational policy setting gives enough consideration to disability equality?

What measures can we put in place and how are we gaining assurance that delivery is effective across the sector?

What evidence are we using to demonstrate progress is being made?

Measuring our progress

Sector disability (single) equality schemes

2.14 The Department of Health produced its first Disability Equality Scheme as part of its Single Equality Scheme in December 2006. Since the first Department of Health Single Equality Scheme was published, there have been a number of achievements, including:

- Better involvement of internal and external stakeholders
- Coverage of the full Department of Health work programme
- Specific action plan developed
- Establishment of an equality monitoring group

> "Our assessments, nevertheless, revealed a number of common weaknesses responding to the Duty's requirements:
>
> - Failure to involve external stakeholders
> - Failure to clearly and transparently indicate how involvement had influenced the Scheme
> - Failure to develop actions across the full range of Departmental functions (with a number focused exclusively on employment). For example, the Department of Health Scheme failed to include any actions regarding its responsibility for social care.
> - Failure to show how they would use the information that they gathered. For example by adopting clear time based objectives across a range of relevant functions"
>
> Issues identified in *'Up to the Mark'*[53] How have Government Departments responded to the new Disability Equality Duty (Disability Rights Commission, 2007)

2.15 The Department of Health scheme was revised in July 2007.A further 2008 revision is being prepared for publication. We recognise that there is scope for improvement and we are learning from past lessons. The revised Scheme will include the following actions for sustainable improvement which are now being put in place across all the equality strands:

- Improving the quality of the data we use to support policy development
- Monitoring the impact of policy
- Developing and disseminating good practice in stakeholder consultation and involvement
- Implementing joint strategic needs assessment and world class commissioning
- Improving access and responsiveness in service provision
- Empowering people to understand and use services
- Promoting equality of opportunity across the NHS and social care workforce, and
- Improving the capacity and capability within Department of Health, and demonstrating how we are holding ourselves to account

2.16 The Scheme also includes specific action to promote equality for disabled people:

- a revised strategy for people with learning disabilities following consultation on *'Valuing People Now'*[54]
- work to support the Government's Independent Living Strategy
- support to development of pan-disability user-led organisations to support commissioning and user involvement
- updated guidelines for the NHS on people who lack capacity to consent

Disability (single) equality schemes in the wider policy sector

NHS Organisations

2.17 The Healthcare Commission reported only 81.5% of NHS organisations had a published disability equality scheme in its 2007 assessment. As part of the work to improve this position, the Department of Health and Strategic Health Authorities have organised a series of 'roadshows' and will be developing further initiatives over the next year, including work with NHS Employers.

Arms Length Bodies (ALBs)

2.18 The Department of Health surveyed it's 24 Arms Length Bodies (listed in Chapter 1) and found nearly 90% had a disability or single equality scheme in place. The majority also had in place arrangements for undertaking (disability) equality impact assessments of their policies and plans. We will continue to work with the Department of Health's Arms Length Bodies to help improve awareness and provide support.

Professional regulatory bodies

2.19 The Department also reviewed the organisations of the Academy of Medical Royal Colleges and other regulatory bodies (list of bodies in Chapter 1) and found nearly 85% were meeting their requirements under the Disability Equality Duty.

Culture of policy making in the sector

2.20 For sustainable progress towards disability equality, the right culture for policy making is needed at both national and local level. Through its Permanent Secretary and Director Generals, the Department of Health now has visible leadership and targeted support to ensure that equality is seen as central to good, evidence-based policy making.

2.21 The Department and the strategic health authorities are not solely responsible for leading the NHS. Independent sources such as local authority Overview and Scrutiny Committees have a role in ensuring NHS organisations pay 'due regard' for disability equality and equality generally. The guidance *'Equal to the task'*[18] has resulted in local NHS strategies and proposals being scrutinised more thoroughly through the lens of equality.

2.22 Organisational culture is important to setting the right environment for achieving equality. The Department of Health equality impact assessment programme has been working with the Department's learning and development specialists to raise awareness of equality and disability, in particular highlighting the fact that sometimes people need to be treated differently to get equal outcomes.

Governance and leadership

> *"Leadership is essential to deliver policy effectively for vulnerable groups of society".*
>
> *Healthcare for All – the independent inquiry into access to healthcare for people with learning disabilities*, Sir Jonathan Michael, 2008[22]

2.23 First outlined in Department of Health's 2006 Single Equality Scheme, the Equality and Human Rights Assurance Group has been established as a key step in strengthening governance arrangements for equality. The Group, chaired by a Departmental Non-Executive Director oversees Department of Health systems for equality and human rights and provides challenge to Departmental directorates.

Equality and Human Rights Assurance Group

The committee has delegated responsibility for providing the Corporate Management Board with assurance on:

- the adequacy of governance arrangements in place for compliance with equality and human rights legislation and the management of associated risk;
- the Department of Health Single Equality Scheme and action to deliver the Single Equality Scheme action plan;
- mainstreaming of equality and human rights into DH policy and business processes;
- the effectiveness of stakeholder management arrangements; options for development and transfer of its functions.

2.24 The NHS Chief Executive has recognised that delivering the equality agenda requires coordinated action across the NHS. He is establishing a high-level equality and diversity board with membership drawn from health and care bodies at national, regional and local level. As with the Equality and Human Rights Assurance Group, non-executive director representation will tap into wider experience and add a greater element of challenge to the NHS.

Equality and Diversity Council overview

The Equality and Diversity Council will influence Chairs, Non Executive Directors, Chief Executives and other Executive Directors on how best to deliver equality and diversity as part of their day-to-day roles and improve accountability for this within their NHS organisations. Both the legal and business imperative for equality will be highlighted through the Council, and this vision will be brought alive for NHS organisations.

Improving communications

Information and communication

"The importance of the provision of information to the public, which is easy to read and understand."

Forum held 23 January 2008 involving 66 disability equality stakeholders.

2.25 The Department of Health is a member of the cross-government group, Images of Disability, led by the Office for Disability Issues to improve the quality and consistency of communications with and for disabled people and to increase the profile of Equality 2025.

Improving involvement

Consultation and Involvement

"Disabled people's expertise should be recognised, they should be given more support and training to give them confidence to participate in consultations more effectively".

"The Department needs to be more proactive and strategic in seeking the views of disabled people and feeding back what is going to be taken forward from consultations".

Comments from disability stakeholder forum, January 2008.

2.26 A repeated theme from our stakeholder events in January and October 2008 was that disability stakeholders are keen to become more involved in our work. These views reflect the findings of the September 2007 report for the Disability Rights Commission '*Involvement for Real Equality: the benefits for public services of involving disabled people*'[28].

2.27 To make sure we respond to this interest, the Department of Health has commissioned an independent review to look at equality stakeholder engagement in a policy environment. A key element of this review is how we identify, engage and involve disabled stakeholders and organisations in the development of health and social care policy. A report with recommendations is expected by April 2009.

Developing service user involvement (National Social Inclusion Programme)

In order to successfully develop service user involvement within the programme there has been a dedicated member of part time staff working on involvement for the past year. The budget drawn up was based on the *Making a Real Difference* guidelines. A budget was set that would enable up to 15 people to sit on the Reference Group and receive a payment of £85 a meeting.

A consultation event was held with existing members to draw up Terms of Reference, a Code of Conduct and Role Description for members. Administration systems were established to ensure swift payment of expenses, sending out of papers and ensuring consistency between meetings. Based on the results of this consultation event all members of the group were invited to interview. Out of the original 45 members, 16 members were interviewed and nine appointed.

2.28 Strengthening the role of local Learning Disability Partnership Boards will be a key element in driving progress for people with learning disabilities. These boards will develop local action plans outlining how they will make the best of the new opportunities for people with learning disabilities and their families and carers. They will report on progress as part of the wider public reports on Valuing People. They will demonstrate how local services are changing as a result of their reviews of person-centred information and support.

2.29 In *'Aiming High for Disabled Children'*[4], the Government made a commitment for all local areas to build on good practice in engaging parents of disabled children, for example through parents' forums. The purpose is to help parents of disabled children to become more actively engaged and to influence the design and delivery of services. *'Together for Disabled Children'*[51] launched a grants programme in September 2008. The programme provides grants to parents groups and supports local advisers.

> *'Persons with disabilities should have the opportunity to be actively involved in decision-making processes about policies and programmes, including those directly concerning them.'*
>
> UN Convention on the Rights of Persons with Disabilities, December 2006[10]

2.30 The NHS needs to understand better when and how it involves users, and how to listen and respond to what it has heard. One of the five pledges to users in Lord Darzi's *'NHS Next Stage Review: Leading Local Change'*[31] is that 'You will be involved'. Currently there is little evidence to show this involvement activity has been taken on board across all areas of the NHS. This includes involvement in decision-making processes; demonstrating how organisations have listened and responded to what users have told them; and how health services have been shaped according to the needs and preferences of users.

2.31 The Department has produced specific guidance on involving patients and the public in health services in *'Real Involvement: working with people to improve health services'*[40]. This will help NHS leaders be more confident in their approach to good involvement practice and will lead to better and more transparent decision-making.

2.32 Primary care trusts are charged with ensuring the views of all users are taken into account in determining their service provision.

Involvement in local strategies: Suffolk Primary Care Trust

Over 800 local people were actively involved in the development of Suffolk Primary Care Trust's commissioning strategy for 2008–13. Events included open workshops led by senior clinicians, and meetings with specific groups such as people from black and minority ethnic communities, people with disabilities, and young people. Local people told the Primary Care Trust that they wanted more help to stay well and the confidence to know that services would be there when they need them. In response to these views, the strategy will focus much more on improving health and preventing ill-health . There are plans to improve access to care and develop more locally-based services particularly in community settings.

2.33 We have also created Local Involvement Networks (LINks) to bring together local people, organisations and groups that want to improve health and social care services in their area. These should make it easier for communities to talk with the people who run services and scrutinise their work. Anyone can become part of a Local Involvement Network, from carers to service users to community leaders and patient representatives.

2.34 The influence of Local Involvement Networks can be considerable. They can make recommendations and expect a response from commissioners and they can refer matters to the local 'Overview and Scrutiny Committee' for action.

2.35 Involving patients and carers in the running of local NHS organisations help make sure that change happens. We have promoted a range of ways of doing this. The NHS Foundation Trusts Boards of Governors for example provide opportunities for disabled people and stakeholder groups to have their say on how their local services should be shaped. We have widely publicised Local Involvement Networks which are accessible to all. Easy read materials describe what they are and how they work.

2.36 We have also brought together experts from both the statutory and voluntary sectors to form the National Expert Group on Mental Health which provides expert advice to the Department and Other Government Departments.

2.37 We are leading work within the Transforming Adult Social Care Programme to support the establishment by 2010 of a user-led disability organisation, modelled on centres for independent living, in every local authority area.

Promoting disability equality in policy development nationally

"Equality impact assessments are not optional… so there is no excuse."

Surinder Sharma, National Director of Equality & Human Rights to Department of Health Arms Length Bodies conference (September 2008)

2.38 We recognise that if we are to make progress on the ground, disability equality needs to be embedded in national policy.

2.39 There is now a new programme for driving the national policy approach on equality impact assessment. It focuses on improving both the coverage and quality of the assessments as a fundamental part of good policy making. The programme will be supported by a new electronic learning tool to improve general awareness; highlighting disability in bullying and harassment training; and understanding that attitude in the workplace impacts on policy development and therefore the promotion of equality. There are also new arrangements in place that ensure due regard is paid to every policy document published for the NHS and social care through the Department of Health.

2.40 Recent high profile, high priority work programmes, including the Cancer Reform Strategy, End of Life Care and the Stroke Strategy – all of which will support better outcomes for disabled people – include outcome based actions.

Cancer Reform Strategy Equality Impact Assessment (action on equality)

A National Cancer Equality Initiative was proposed, bringing together key stakeholders from the professions, voluntary sector and academia to develop research proposals on cancer inequalities, test interventions and advise on the development of wider policy.

End of Life Care Equality Impact Assessment (improving competence)

Skills for Care and Skills for Health, in partnership with the NHS End of Life Care programme and the Department of Health, are developing a set of common core principles that will improve the competency of health, social care and others who have a role in end of life care through improved training and education.

Stroke Strategy Equality Impact Assessment (strategy development and outcomes)

A successful outcome from the implementation of the stroke strategy would see equal improvements across the whole of the population of England regardless of population group. Ideally, we would also see some ‘levelling up’ so that there was a better than average reduction in the number of strokes in those groups which are now disproportionately susceptible to the illness. The specific outcomes involved are:

- a reduction in the number of strokes of all kinds;
- a reduction in the number of mortalities and the severity of disabilities from stroke;
- fair access to services and health improvement;
- the provision of better quality treatment and care for stroke patients, stroke survivors and their carers throughout the whole of their treatment and care and in all aspects of their life including returning to work, leisure and community activities;
- a greater understanding by the public and all the health and social care professions involved of the factors that contribute to the risk of stroke; recognising the symptoms of a possible stroke; how to deal with someone who may be having a stroke; and knowing that stroke is an emergency condition requiring immediate medical attention; and
- the removal of any barriers which disadvantage any group in achieving the other five outcomes.

2.41 The Equality Impact Assessment of *World Class Commissioning*[58] is providing a valuable opportunity to raise the profile of equality in Board leadership development as well as for disabled patients, through the improved commissioning of care.

2.42 We are already seeing more joint working between the Department of Health and other Government Departments on Equality Impact Assessments including the Department for Children, Schools and Families on the Child Health programme (and strategy) and Department for Work and Pensions on the response to the Dame Carol Black review report '*Working for a healthier tomorrow*'[57] . Both have informed and led to better co-ordinated delivery.

We have brought together experts from both the statutory and voluntary sectors to form the National Expert Group on Public Mental Health. The group will provide expert advice to the Department of Health and Other Government Departments on evidence, good practice and recommended policy directions. Its aims are to promote well-being within the population; and to facilitate shared learning and the development of innovative new ways of working.

Improving access to psychological therapies Equality Impact Assessment[24]

Promoting disability equality in policy development through the NHS and social care sector

2.43 Work is being undertaken to broaden awareness of disability equality at local level. We have produced '*10 Steps to your SES: A Guide to developing a single equality scheme*'[44] and established Single Equality Scheme learning sites. We will consider how the results of these are evaluated. Further guidance on disability equality schemes for the NHS will be published alongside disability equality guides during 2009. A learning disability guide is being prepared for release in early 2009.

2.44 Guidance issued by the Government Equalities Office, '*Equality and Diversity in LAAs: An Aide Memoir for Locality Managers*'[20] is also helping sharpen the focus at local level. Considering equality in an LAA context is helping Local Strategic Partnerships achieve better outcomes for disabled people.

2.45 We are working in partnership with Strategic Health Authority Equality Leads on practical application of Equality Impact Assessments and Disability Equality Schemes, sharing lessons learned. We are also working with the Healthcare Commission to build on lessons from their sector assessments nationally and to provide a steer on areas of concern.

Improving performance management and measuring progress

Implementation at a local level

"The Department should implement performance measures and financial penalties for Trusts not fulfilling their legal duties under the Disability Discrimination Act".

Comment from disability stakeholder event, January 2008

2.46 Whilst there has been a clear focus in the Department on improving equality impact assessments, other mechanisms are also important. During the January 2008 stakeholder event, disabled people and disability stakeholders suggested the NHS should be held to account for meeting disability equality duties. We agree with this, the new arrangements for the Statement on Internal Control, outlined below is a significant step in that direction.

2.47 Within the Department of Health itself, the introduction of the Capability Review for Government Departments has provided a consistent focus on delivery with regular assessments and public disclosure acting as clear incentives to improved performance. Although there is some way to go, the regular staff surveys undertaken in the Department of Health show we are making progress and aspects of this progress are set out in Chapter 6 of this report.

Local planning and performance

2.48 The '*NHS Operating Framework 2008/09*'[47] signalled the importance of primary care trusts better planning their services so that equality is embedded. The Department is now taking steps to define for the first time a 'Vital Sign' relating to learning disabled patients.

2.49 A disability indicator, based on a survey of parents and carers of disabled children, will form a core part of local performance management arrangements. The improvement of the quality of services for disabled children is a key priority of the Child Health and Well Being Public Service Agreement. This indicator also forms part of the local government National Indicator Set and Vital Signs within the NHS Operating Framework.

Gaining assurance at local level

2.50 From April 2009, Accountable Officers of NHS organisations will provide assurance that their organisations comply with equalities legislation through annual Statements on Internal Control. These are published as part of each organisation's audited annual accounts and will be used to consider the overall equality performance for the sector.

This is a mandatory disclosure and is required to provide assurance that measures are in place to ensure compliance with the organisation's obligations under equality and human rights legislation, so that strategies, policies, functions and service delivery do not discriminate against employees or sections of the community. This includes ensuring service provision is compliant with human rights, disability, gender and race equality legislation. All organisations should have such measures in place and the disclosures should read:

"Control measures are in place to ensure that all the organisation's obligations under equality, diversity and human rights legislation are complied with"

Additional information should be appended to the disclosure if, for example, there are or have been problems with control measures.

Statement on Internal Control wording

Assessing local services

2.51 From April 2009 the Care Quality Commission will assume the responsibilities of the Healthcare Commission, Commission for Social Care Inspection and the Mental Health Act Commission. The high-level framework for the requirements against which local health and care providers will be assessed, from 2010/11 onwards, will take account of the needs of seldom heard groups. The requirements will cover safeguards to people when they are vulnerable and the assessment, planning and delivery of care in a way that reflects people's individual needs and their diversity. We expect a review of equality and diversity in health and social care will form part of the Care Quality Commission's initial work programme.

Procurement as a lever for disability equality

2.52 As part of the Equality Bill proposals, the Government announced it will explore ways in which public procurement can be used to further equality outcomes. This will cover a range of both legislative and non-legislative options.

2.53 The Office of Government Commerce has convened a cross-Government working group (Government Equalities Office; Her Majesty's Treasury; Department for Business, Enterprise and Regulatory Reform; Department of Communities and Local Government; and Department for Work and Pensions) to take forward this work.

2.54 The group will examine a range of options for using public procurement to further equality outcomes in ways that achieve value for money in our spending of taxpayers' money, while taking account of the need to minimise the burdens placed on both the public and private sectors. Once agreed, proposals will inform work being undertaken on the new Equality Duty and the Equality Bill proposals as a whole.

2.55 The group will be supported by a stakeholder consultation group, consisting of representatives from the private and public sectors and from key interest groups.

Providing evidence for the progress of disabled people

2.56 The development of Equality Impact Assessments continues to highlight the need for better quality evidence. The Equality Impact Assessment of the manual of cancer services clearly identified a lack of data and proposed arrangements to address this.

Manual of Cancer Services Equality Impact Assessment (data availability)

Where the Cancer Reform Strategy identified that there is a lack of data, the peer review process provides a mechanism for ensuring that data is collected. It monitors compliance with requirements for the minimum dataset. This specifically identifies ethnic groups.

The CRS identified that there has been limited data in the past with regard to BME groups and disabilities. The Peer Review Programme plans to collect better information which may contribute to inequalities, on all patients and, from this, will be able to assess the impact of measures on those patients. This information will be used to feedback into revised measures and used to provide evidence to establish and inform other work programmes.

2.57 Work is underway, led by the Office of National Statistics and the Office for Disability Issues, to address disability data availability, disaggregation and consistency. The report from the cross-government working group is due in early 2009 and the Department of Health will support NHS organisations to implement its recommendations as part of its overall data equality strategy. In the meantime, the Department and the Information Centre plan to improve their marketing of the available patient experience survey data as useful indicators of the progress of disabled people and people within other equality strands.

2.58 The self-reported experiences of disabled people in 2007/08 has provided the baseline data set for the purposes of 'Access' in Chapter 3 of this report.

2.59 The Department has set up an Equality Monitoring Group bringing together experts from across policy, information, performance and delivery organisations. This has helped bring a much more focused approach to improving, collating and analysing data on equality. The Group will take forward recommendations from the cross-government group that is considering how best to record information on disability in the public sector. It is also leading work at national level to look at whether the key indicators for measuring NHS performance show significantly different outcomes for people in different equality strands. The analysis will cover outcomes for disabled people where data is available and recommend action to fill gaps where it is not.

2.60 Over time, this will help track outcomes for disabled people compared to other patients and service users and begin to build a much richer picture of progress towards achieving disability equality in the health and social care sector, addressing some of the criticisms made in '*Up to the Mark?*'[53].

2.61 '*Aiming High for Disabled Children*'[4] provided a public commitment to delivering: "better local level data on disabled children and regular monitoring of the progress made on improving outcomes for disabled children, with much greater use of comparisons across the country to judge how different local areas are performing". The planning and commissioning of high-quality, responsive services requires agencies to collect and make effective use of accurate and reliable data. Services for disabled children are provided across three or more different agencies and there are currently a number of different (and uncoordinated) data collections in place across those agencies.

2.62 An 'Improving Data Expert Working Group (IDEWG)' has been established to identify necessary improvements. Its membership includes key stakeholder representatives from the Department of Health, Department for Children, Schools and Families and the Office of National Statistics, as well as policy makers, analysts and managers from local agencies.

Conclusions

Shaping the environment for disability equality improvement

- The sector leaders are demonstrating a desire to create a culture that not only values disability equality, but is directing activity that requires performance to be managed
- Good progress is being made to develop an environment and systems that allow for good, evidence based, equality impact assessed policy
- The sector as a whole is learning from past underperformance and is working together to ensure good progress is made to address these
- Better use of performance monitoring techniques will identifiy opportunities for improvement and will ensure progress is made across organisational boundaries

The following chapter describes how we are making health and care services more accessible for disabled people.

Chapter 3: Working towards equality of access and integrated care

This Chapter outlines:

- **Progress made in addressing underperformance identified in general healthcare services but there is a lot of work underway to put things right.**
- **How we are making information more accessible.**
- **How we are improving accessibility to health and social care for the whole population.**

Introduction

3.1 Access is often the biggest barrier to equality for disabled people. It can be a problem in all areas of modern living. The health and care services sector is no exception.

3.2 This chapter focuses on patient and care users' initial experience of access to general health services. We have looked in particular at patient satisfaction in GP services. We have also considered the management of long-term conditions, which crosses primary care, community health services and hospitals. There are around 15 million people who have one or more such conditions. They need to feel confident that they have the choice, control and convenience they want from local services.

3.3 We also need to ensure that disabled people can access services such as dentists or opticians in the same way as non-disabled people. Patient satisfaction surveys are now giving us the kind of information that allows us to meet those needs.

3.4 We are improving the way we collect routine information so that we can break data down by disability or impairment. We make that information freely available through the Information Centre (subject to legislative controls on information). The accessibility of this information means health and care services can plan, prioritise, and provide services that reflect people's lifestyles and aspirations.

Our considerations in determining progress:

How is the policy sector working towards eliminating barriers?

What progress has been made by the Department of Health and the NHS in responding to the Disability Rights Commission Formal Investigation 'Equal Treatment – Closing the Gap' and the Mencap Report (2004)?

Are disabled people experiencing similar levels of satisfaction to non-disabled people in accessing health and care services and are they seeing the benefit of improved access to GP services?

What provision has been made for access to health and care services for children?

How are we providing access to health and care services for people in non-traditional settings?

Responding to sector underperformance

Sector response to the Disability Rights Commission

3.5 The 2006 Disability Rights Commission (DRC) report, *'Equal Treatment: Closing the gap'*[19] examined the physical health inequalities faced by people with learning disabilities and/or mental health problems. Assessing the journey of each patient through the healthcare system, it found inequalities in all stages:

- recognising a health need
- seeking and accessing primary care
- checks, screening and health promotion support
- diagnosis, treatment and support
- seeking feedback and involvement

3.6 The report found that learning disabled people and people with mental health problems are much more likely to have significant health risks and major health problems than other citizens. For learning disabled people, obesity and respiratory disease are particularly prevalent. For people with mental health problems, obesity, smoking, heart disease, high blood pressure, respiratory disease, diabetes and stroke are more common. Yet these high-risk groups report greater difficulties in accessing healthcare and there have been well-documented performance issues in the quality of some healthcare for these groups.

3.7 Following the Disability Rights Commission's report, the Department published 'Promoting Equality', its action plan to address the DRC's recommendations, and formed a steering group to drive action. The group has a key role in helping to promote Department of Health and NHS actions that improve access to and quality of healthcare for people with learning disabilities and/or long-term mental health conditions. The group's key deliverables include annual health checks, improved service commissioning of services

NHS Education and Training

- A National Framework for Disability Equality & Etiquette Learning (DEEL) for health and social care services was launched by the (then) Disability Rights Commission and the Department of Health.
- *Treat me Right* guidance on working with people with learning disabilities has been developed with the Academy of Medical Royal Colleges.
- The Department, the Equality and Human Rights Commission, the main professional regulatory bodies and education commissioners working together to help better embed learning disability and human rights in undergraduate curricula for doctors, nurses and other healthcare professionals.

Information and IT

- Two specific learning disability indicators have been included in the Joint Strategic Needs Assessment minimum data set.
- The Department is working with the NHS Information Centre to improve the information and information systems needed to monitor equality of access to healthcare for disabled people.
- We are introducing a new NHS 'Vital Signs' indicator on the number of people with moderate or severe learning disabilities who receive annual health checks.

Screening

- The National Screening Programme is reviewing screening programmes to identify ways of improving equality of uptake for people with learning disabilities.

and improving education and training for NHS professionals.

Access to healthcare for people with learning disabilities

3.8 *'Death by Indifference'*[15], highlighted performance issues in health services in the cases of six people with learning disability. These are now subject to investigation by the Health Ombudsmen. The report of the independent Inquiry into access to healthcare for people with learning disabilities set up by the then Secretary of State under the Chairmanship of Sir Jonathan Michael – *'Healthcare for All'*[22] – was published in July. It confirmed that the cases in the Mencap report were not isolated incidents.

3.9 The Government's response to the key recommendations of *Healthcare for All* will be published in '*Valuing People Now*', the cross-government strategy on services and support for people with learning disabilities.

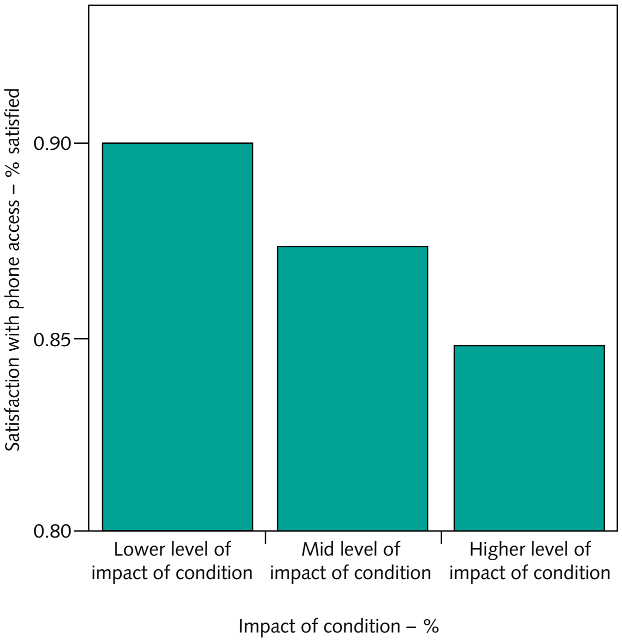
3.10 To maintain momentum in improvements the NHS Chief Executive has written to all strategic health authority Chief Executives asking them to report on how well they are supporting disabled people. In particular, he has asked how they are improving access to general health services for people with learning disabilities, which reflects both recommendations from the Disability Rights Commission and the Independent Inquiry. The Secretary of State will also raise this issue during his regular meetings with NHS Chairs.

Levels of satisfaction with access

3.11 In 2007/08, nearly two million patients responded to the national GP access and choice surveys. This has enabled us to take a view nationally. But even more importantly, it allows healthcare planners to look at local patterns of patient satisfaction, broken down by factors such as deprivation, disability, ethnicity and other factors. This information will help shape services that meet the needs of the local populations. By making the information publicly available, disabled people will for the first time be able to judge how their experience of services compares to that of non-disabled people.

3.12 Our early analysis shows that while satisfaction with primary care services is generally higher for disabled people than for non-disabled people, there are differences across impairments.

3.13 Reported levels of satisfaction for people with learning disabilities are lower than for non-disabled patients. When broken down, we found telephone access was a good indicator across all demographic groups. For people with learning disabilities, we found a clear link between the impact of their condition and satisfaction levels, with satisfaction increasing as the impact of their condition lessens. This is illustrated below.



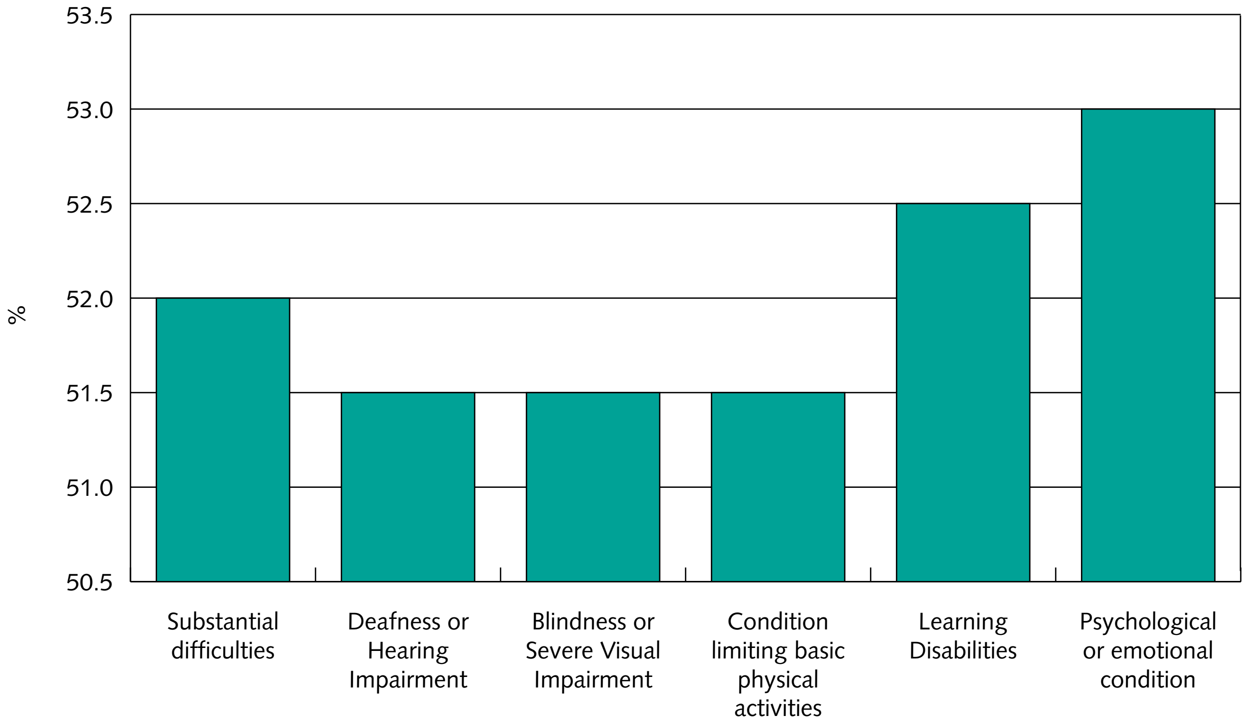
3.14 This picture of relative user experience is echoed in the '*Closing the Gap*'[19] report, with the Area Studies reporting that '*the process of making appointments was a frustrating experience for most of the people we talked to*', often for reasons relating directly to their impairment. For example, the requirement to book appointments in advance was difficult for some people. One person commented that *"It is difficult to make an appointment because you have to be good on the phone and that is too hard because people always talk too fast on the phone and you can't think quick enough to answer them"* (DRC 2006-Results from questionnaires for people with learning disabilities and/or mental health problems. Area Studies Report – *Closing the Gap*).

"when I ring up, I can't get an appointment……. when my carer or someone else rings, they can get an appointment"

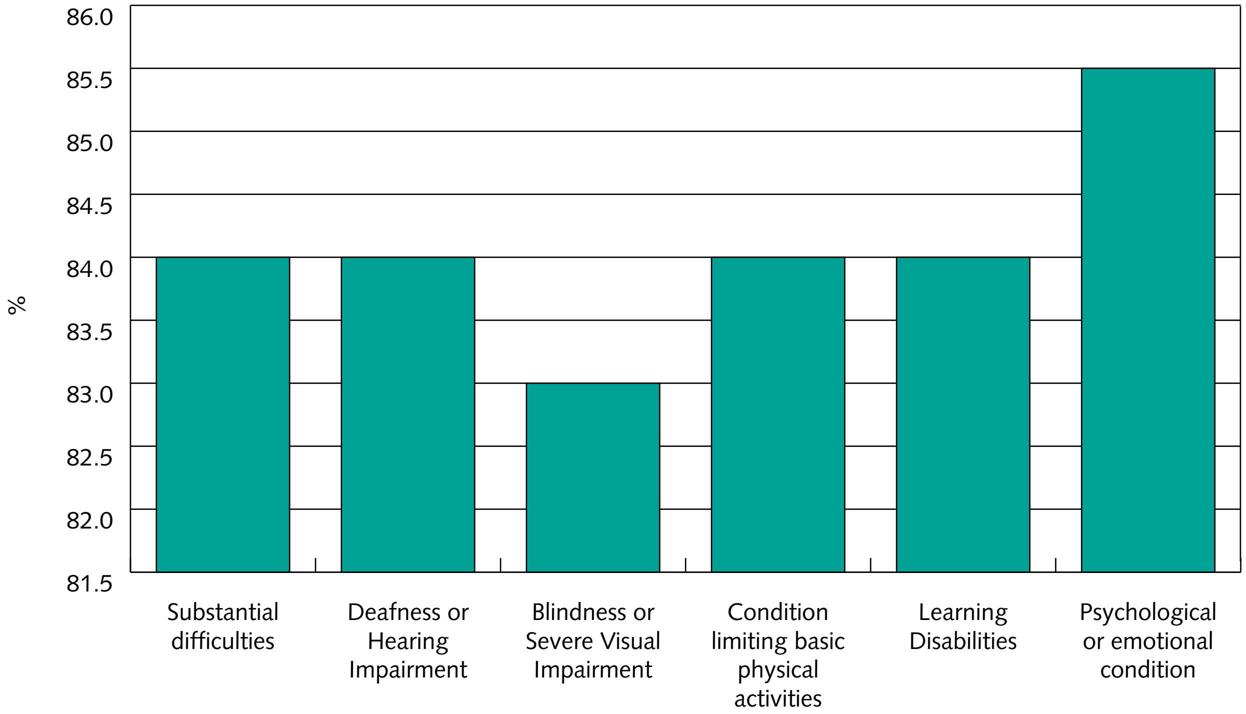
Participant comment from the stakeholder involvement event, October 2008

3.15 There is some variation in experience of being offered choice (when being referred for hospital treatment) between disabled people and non-disabled people. The introduction of data broken down by impairment will allow primary care trusts to work with GP practices on addressing differences in satisfaction levels. The results from 2007/08 show significantly lower levels of satisfaction for patients who are blind or have severe visual impairments.

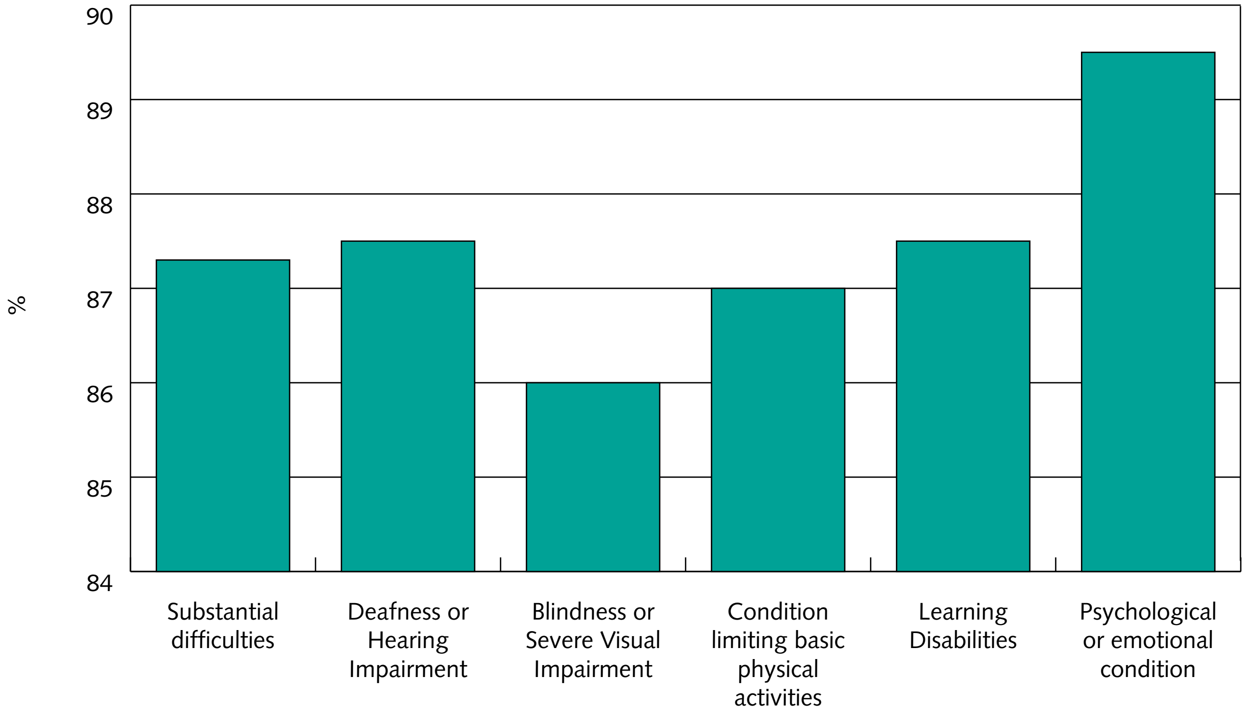
Hospital choice – percentage where choice was discussed when referred



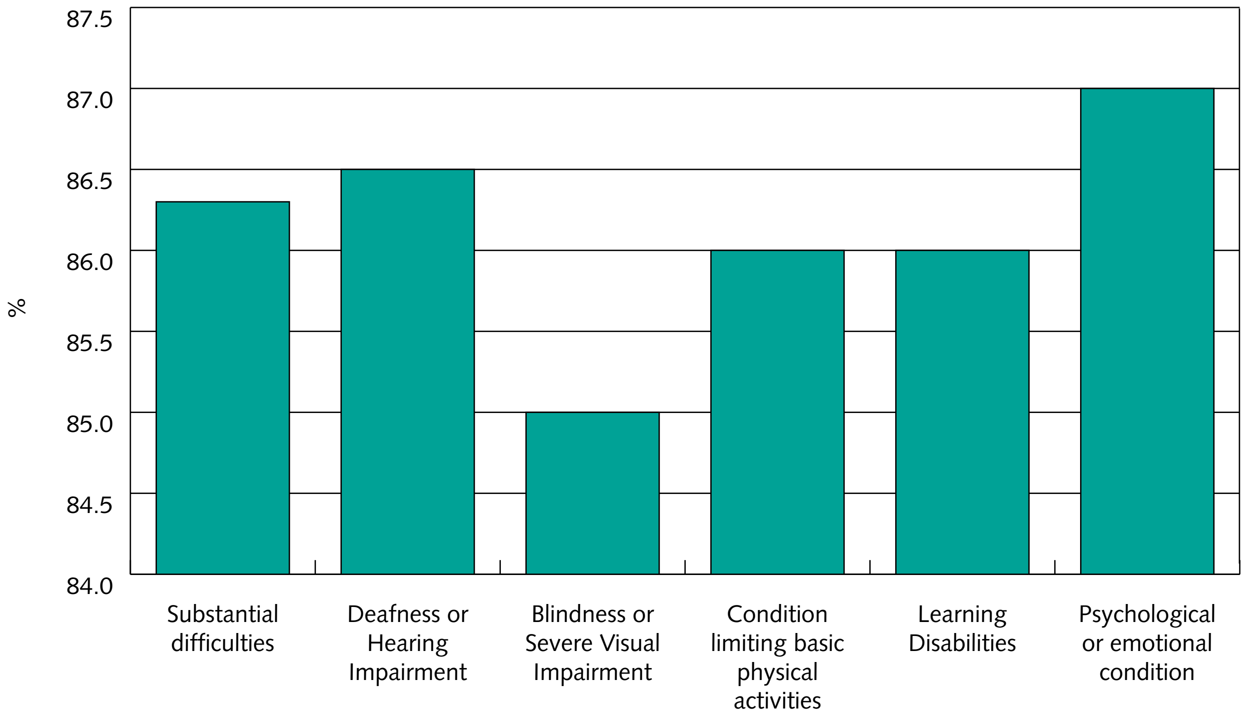
Overall Satisfaction



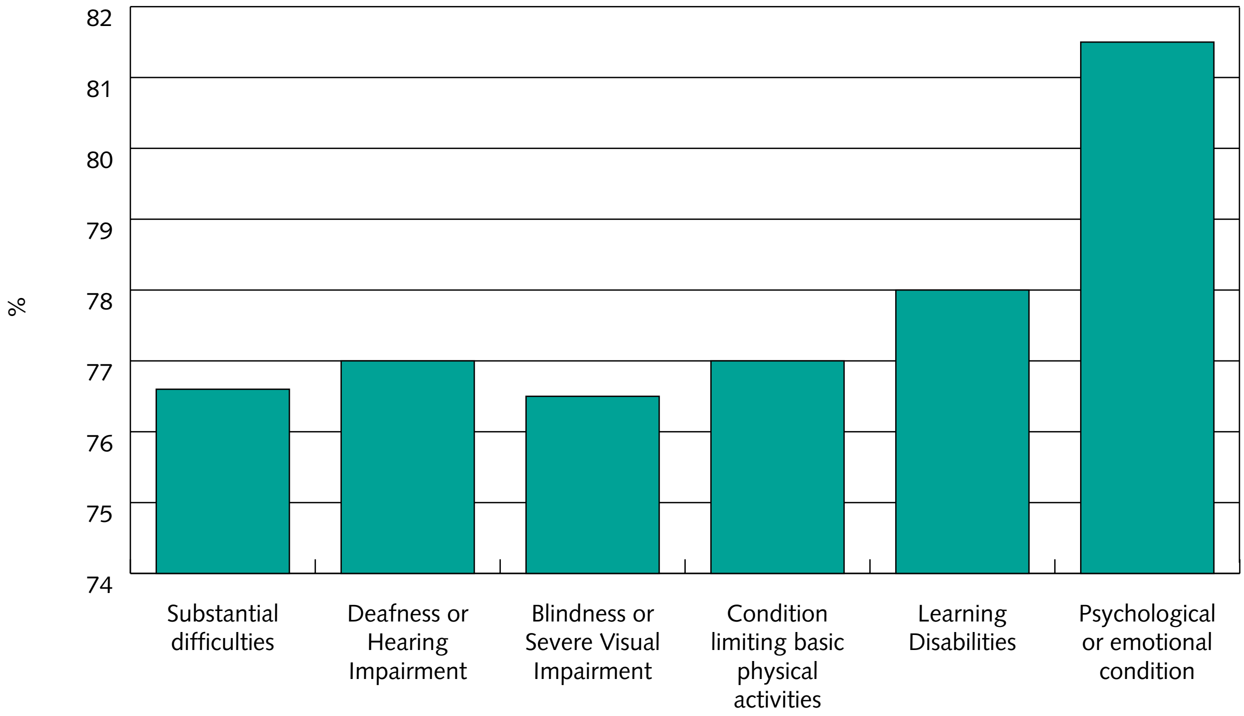
Satisfaction with phone access



48 hour GP access – percentage able to get appoinment in 48 hours



Advance appointment – Percentage able to book 2+ days ahead



3.16 The more detailed analysis identifying patterns of relative satisfaction with GP services (by area) will support primary care trusts in targeting their work with practices to improve awareness and training. The equality and human rights function within the Department of Health will work in partnership with strategic health authority equality leads to drive forward their work.

Improving primary care services

3.17 In 2007, the Department worked with NHS Primary Care Contracting to develop a framework to help PCTs commission enhanced primary care services for people with learning disabilities, including annual health checks, health action plans and health facilitators. The Valuing People Support Team has been working with the NHS to promote the use of this framework.

3.18 In September 2008, NHS Employers (on behalf of the Department of Health) agreed new arrangement with the General Practitioners Committee of the British Medical Association to provide annual health checks for people with moderate or severe learning disabilities known to local authorities. Primary care trusts will be directed to ensure that all GP practices in their area have the opportunity to provide these enhanced services, which form part of a £50 million programme of additional investment in GP services to improve quality of care in particular areas.

3.19 As part of the Directed Enhanced Service for annual health checks, GPs and practice staff will need to receive training in relation to learning disability. This should help improve the ability of GP practices to provide more responsive services, both for people with learning disabilities and more generally for patients with specific individual needs.

Delivering better access to patients with mental illness

3.20 There are a number of other initiatives underway to improve access for disabled people. Primary care trusts, for example, now have best practice guidance on how to meet the physical health needs of people with severe mental illness.

3.21 In 2006, we published '*Choosing Health: Supporting the physical health needs of people with severe mental illness*'[9]. This helps primary care trusts plan for, design, commission and monitor services that will deliver improved physical health and wellbeing for people with severe mental illness. It shows how a physical healthcare programme should be led, and describes the roles and responsibilities of those involved along with relevant case studies. In addition, £7 million has been allocated to primary care trust baselines to fund wellbeing nurses. They will provide physical health care checks and support healthy living groups, in conjunction with other healthcare professionals, for people with severe mental illness.

World Class Commissioning

World Class Commissioning is about delivering better health and well-being for all member of local populations, improving health outcomes and reducing health inequalities.

The World Class Commissioning[58] programme includes four main strands of work:

- Articulating a **vision** for what world class commissioning can achieve, telling a clear narrative to the NHS to align understanding of the role of commissioning;
- Setting out the **organisational competencies** that a world class commissioning organisation will need to demonstrate;
- Developing a **commissioning assurance system** to hold commissioners to account and to reward performance and development;
- Access to **support and development** tools and resources to help commissioners achieve world class commissioning.

The eleven world class commissioning competencies set out the knowledge, skills, behaviours and characteristics expected of world class commissioners. They describe the processes that, when developed to a high level, will deliver improvements in health outcomes over time.

3.22 The NHS Next Stage Review sets a clearer focus for the NHS on promoting health and wellbeing. This means preventing ill health, not just detecting it and curing it.

3.23 Health checks for people with severe mental health problems have been incorporated into the systems of the majority of GP practices, thanks to GP contract incentives. An analysis of data from the first year of these incentives, carried out as part of this investigation report, showed that 76% of practices reported having provided health checks to at least 90% of their patients registered with severe mental health problems.

3.24 *World Class Commissioning*[58] is the underlying delivery vehicle for many of the objectives of current health policy, including improving services for disabled people, their families and carers. The *World Class Commissioning*[58] programme particularly supports improving and emphasising the engagement of the public and patients, collaborating with clinicians and promoting innovation and improvement. Ultimately, this will give disabled people more choice and control over the services provided so services will become more personalised, integral to delivering improvements. The commissioning assurance system will hold commissioners to account, reward improvement and ensure local health outcomes are improving, a powerful and rigorous process that will drive change.

3.25 As part of the '*World Class Commissioning*'[58] programme, the Department is working with primary care trusts to help identify and spread best practice in commissioning services to meet the needs of learning disabled people. This includes best practice in needs assessment and in engagement with service users, families and carers. This will form part of the Joint Strategic Needs Assessment (JSNAs), undertaken with local authorities and other community partners.

3.26 The minimum dataset for Joint Strategic Needs Assessments 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.

3.27 The core dataset should be the 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 in their areas.

At the January 2008 Disability Stakeholders Forum, services that were more convenient and more designed around the user were common themes. Other issues raised included:

- better information locally to increase access to health services;
- greater consistency in the health and social care sector in different parts of the country;
- encouragement of patients' ownership and management their health as they get older;
- advocacy services to help disabled people access services;
- awareness that the needs of disabled people change throughout their lives.

Access to Primary and Community Services

Access to psychological therapies

3.28 *'Securing Better Mental Health for Older Adults'*[42] acknowledged that older people have not benefited from some of the developments in mental health services for younger adults. It therefore set out the principle of age equality for future service provision.

3.29 *'Improving Access to Psychological Therapies (IAPT) Equality Impact Assessment'*[24] identified the need to better explore how it could align with the Long Term Conditions (LTC) programme. The Improving Access to Psychological Therapies programme has been working with a number of pathfinder sites to consider the particular challenges of providing services for older adults.

3.30 The majority of disabled people are older people. Commissioners are required to consider services for older adults as an integral element of their overall service provision.

3.31 Of the 9663 people who were assessed by the Improving Access to Psychological Therapies pathfinder sites, disability status was recorded for 62%. There was only an 8% recording for mobility status. In general, the programme has taken a broad view of the potential impact on people with a range of disabilities. For example, the programme is in discussion with the British Society for Mental Health and Deafness with a view to understanding the needs of those who communicate using British Sign Language (BSL) and how services can be made more accessible. For those users of British Sign Language this is more of an issue of communication than disability.

Access to occupational therapy

3.32 Health and wellbeing are influenced by a person's ability to engage in everyday life. Occupational therapists help people with a wide range of needs to achieve maximum independence and autonomy. They advise, for example, on types and use of equipment that should be used during recovery or rehabilitation. They also have the skills to train and supervise other equipment assessors to ensure they are competent.

Access to community equipment services

3.33 For many disabled people community equipment and wheelchair services provide a significant gateway to independence. We set out our commitment to transform community equipment in both *'Aiming High for Disabled Children'*[4] and *'Putting People First'*[39], the Government's vision of the future of adult social care.

Question	Positive response (Satisfied)	Neutral	Negative response (Unsatisfied)
Are you happy with the help you have received?	95%	4%	1%
Were you happy with the way those who discussed your needs treated you?	87%	2%	10%
Did you feel that you had a choice about what equipment or adaptation to you home you had?	80%	–	19%
How well were you kept informed?	92%	–	8%
The equipment/adaptation has improved the quality of my life?	90%	8%	2%

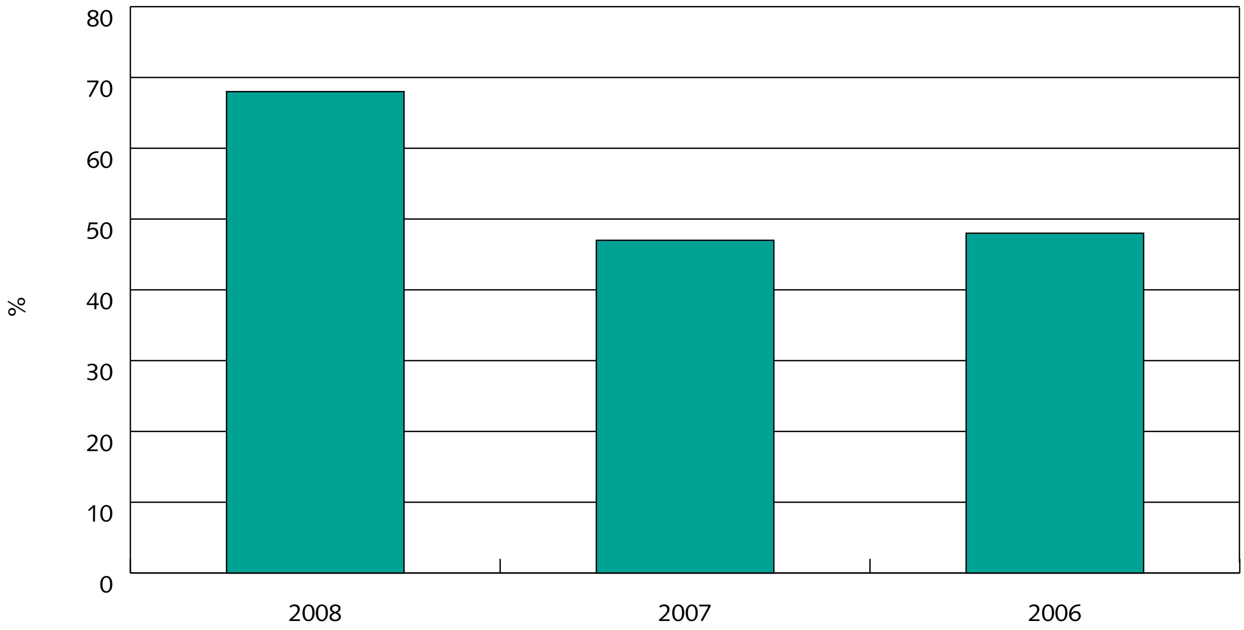
3.34 The community equipment model has been improved through an 18-month consultation process with key stakeholders including service users and carers service managers, occupational therapists, and practice nurses. This process included 18 public forums in nine cities throughout England and working with five local authority and health partners in the North West.

3.35 The new system will change the way that equipment is provided with accredited retailers exchanging equipment for a prescription. This model of service delivery will give state suported users a choice that they have not previously enjoyed. There will also be the option of switching existing prescriptions to a different product within the same functional range to suit the user's lifestyle or preference.

3.36 In February 2007, the user survey showed respondents were positive about their access to community equipment. Above is a summary of some of the responses:

3.37 The chart above shows primary care trusts' compliance with the existing standards improved in 2008 compared with 2007. In

Community Equipment – Percentage of 'achieved'



2006 numbers asessing were low due to the reorganisation.

Access to children's equipment

3.38 The Department is leading the development of a model of provision for children's equipment and wheelchairs through the Child Health Strategy. We are also developing an action plan, backed by £12 million, which will respond to recommendations made by John Bercow MP following his review of services for children and young people with speech, language and communication needs.

Access to community dental services

3.39 '*Valuing People's Oral Health: A good practice guide for improving the oral health of disabled children and adults*'[54] recognised the need for primary dental healthcare professionals to work across professional boundaries. This multi-professional approach includes health professionals, childcare and education services, social care professionals and the voluntary sector. Primary care trusts are responsible for providing or commissioning dental services for all groups and have been encouraged to give particular attention to making services more responsive to the needs of at-risk groups such as disabled adults and children. The NHS community dental services play a particularly important role in arranging appropriate preventive programmes and in providing services for people who may have difficulty in accessing general dental services, for instance by arranging home visits for those with mobility problems.

3.40 The inclusion of dentistry in the '*NHS Operating Framework for 2008/09*'[47] has further raised the profile of dentistry and required strategic health authorities to monitor improvements in access to dental services.

Access to sight tests

3.41 *Action for Blind People* commissioned a survey of over 2,000 people in Great Britain on their attitudes towards eye tests. The key findings from the July 2008 report were:

- 27% (1 in 4 adults) did not know an eye test could prevent them from losing their sight
- 11% (1 in 10 adults) could not provide an answer when asked the purpose of an eye test
- 27% (1 in 4 adults) had not had an eye test in the last two years.

3.42 Free NHS-funded sight tests are available for children under 16 and for young people between 16 and 18 in full time education, people aged 60 and over, those with diabetes or glaucoma or at risk of glaucoma, people on a low income, or those requiring complex lenses or registered as blind or partially sighted.

Diabetic Retinopathy

3.43 Diabetic retinopathy is the most common cause of blindness in working age people in the UK. If untreated, 50% of those who develop proliferative diabetic retinopathy will lose their sight within two years, and some of these within 12 months. Early detection of sight-threatening diabetic retinopathy and treatment halves the risk of sight loss.

3.44 Local Delivery Plan Returns indicate that 85.7% of people with diabetes were offered screening for diabetic retinopathy in the previous 12 months. More people with diabetes are now being offered screening for retinopathy than ever before and to higher standards. At December 2007 there were some 2.06 million people diagnosed with diabetes; 1.67 million people were offered screening. When the target was set in 2003, there were only 1.3 million people diagnosed. Many primary care trusts have achieved the target, with the vast majority offering screening to over 95% of people with diabetes.

3.45 Screening for diabetic retinopathy has been included in the *NHS Operating framework 2008-09*[47]. This drives progress through recovery plans agreed between strategic health authorities and primary care trusts where primary care trusts are not meeting national requirements.

Access to palliative care

3.46 People with, or representing people with, learning disabilities were asked whether they feel inequalities exist in end-of-life care and how the service could be made fairer.

3.47 Short breaks from caring were identified as a priority. Caring for someone with a learning disability can be both rewarding and stressful. It is important to ensure that carers are given as much access to short breaks from caring as those looking after patients with physical illnesses.

3.48 More training is needed for those working with people with learning disabilities as part of end of life care. The *Books Beyond Words*[7] project, supported by the Department of Health through Section 64 funding, will help ensure that people with a learning disability have access to information about end of life issues. *Books Beyond Words* will include guidelines for carers, supporters, health professionals and voluntary organisations who work with people with learning disabilities.

3.49 The Department has also been working with key stakeholders to produce the first ever national strategy for children's palliative care – '*Better Care, Better Lives: improving Outcomes and Experiences for Children, Young People and their Families Living with Life-limiting and Life-threatening Conditions*'[6]. The Government has identified significant funding for both the health service and local government. This will include new investment to boost the provision of vital services for all disabled children (including those with palliative care needs) while giving them and their families a real choice about how and where those services are delivered. End of Life, palliative care services is a priority in the '*NHS Operating Framework for 2008-09*'[47], and we expect significant progress to be made in this area.

Provision for disabled children, including access to childcare

3.50 '*Aiming High for Disabled Children*'[4] included additional funding of £35 million from the Department for Children, Schools and Families (for the period 2008-09 to 2010-11) to reduce attitudinal barriers and improve access to childcare for disabled children and young people and children. This joint Department of Health/Department for Children, Schools and Families project will test out ways of meeting the needs of disabled children as identified in the childcare sufficiency assessments completed by local authorities in April 2008.

Health and care in other settings

3.51 Person-centred planning and health action planning are particularly important for people who are in prison or subject to community sentences. As part of offender management health screening programmes, offenders' learning disability, physical and mental health issues are being identified (which should form the start of an individual's Health Action Plan) enabling access to appropriate education and rehabilitative programmes.

Over half of all elderly prisoners suffer from a mental illness, the most common being depression which can emerge as a result of imprisonment (Annual Report 2006/07, HM Chief Inspector of Prisons for England and Wales, January 2008). Some older prisoners will have a physical health status of ten years older than their contemporaries on the outside.

Doing Time: the experiences and needs of older people in prison, Prison Reform Trust, 2008[17]

3.52 Primary care trusts assumed full responsibility for the provision of healthcare in prison settings in 2006. Social care needs are reportedly largely unmet and there have been difficulties experienced by older people with disabilities in obtaining equipment such as walking sticks or wheelchairs. Although the majority of prisons have Disability Liaison Officers, prison staff report difficulty in establishing who has the duty to provide services.

3.53 As part of joint efforts to improve this situation, the Ministry of Justice is working with us to test the provision of community-based treatment. This will involve coordinated action working between HM Courts Service (HMCS), The Probation Service and the Learning Disability/Mental Health NHS Trusts. The 'Mental Health Liaison Scheme' will involve HM Court Service working with Mental Health Trusts to fund the provision of a full-time senior psychiatric nurse based at court and the services of a consultant forensic psychiatrist available one day a week.

3.54 To better understand how well we meet health needs in prisons, the Mental Health Act Commission survey *'Count Me In'*[12] will be extended into prisons. The aim is to encourage high quality, sustainable ethnic assessments, monitoring and record keeping. This data will then provide a baseline against which to measure changes in mental health services in the future and understand the experience of the diverse range of service users in order to encourage the provision of culturally relevant and appropriate services.

Learning Disabilities: *Positive Practice, Positive Outcomes: A handbook for Professionals in the Criminal Justice System working with offenders with Learning Disabilities.*

Published by the Care Services Improvement Partnership (CSIP) this handbook supports compliance with the Disability Discrimination Act 2005 and responds to the duty to eliminate discrimination and harassment of disabled people and promote greater equality of opportunity for disabled people, including interactions between people with learning disabilities and the criminal justice system. The aims of the handbook are to help Criminal Justice professionals to:

- Recognise when a person has learning disabilities;
- Improve their communication with and support to people with learning disabilities;
- Establish and maintain links with local learning disability services and other support services;
- Be aware of the legislation in place to protect people with learning disabilities

3.55 The Healthcare Commission undertakes an annual inpatient survey. Similar surveys of adult inpatients were also carried out in 2002, 2004, 2005, and 2006. They are part of a wider programme of NHS patient surveys, which cover a range of topics including community mental health, health services for children and young people, accident and emergency care for adults, and ambulance and primary care services.

Inpatient mental health services compare poorly to general acute inpatient. With only slight increase in satisfaction level, using 'excellent' as the marker with a slight, gradual increase from 25% in 2004 to 27% in 2008 whereas adult inpatient general care was rated 'excellent' by 42% in 2004 albeit dipping and returning to 42% in 2007 (the latest year available).

Patients	**Mental Health** Overall, how would you rate the care you received?					
	Excellent	**Very good**	**Good**	**Fair**	**Poor**	**Very poor**
2004	25	29	22	14	5	4
2005	25	29	23	14	5	4
2006	26	28	23	14	5	4
2007	26	29	22	14	6	4
2008	27	29	22	13	5	3
	Acute – Adult Inpatient Overall, how would you rate the care you received?					
	Excellent	**Very good**	**Good**	**Fair**	**Poor**	
2004	42	36	14	6	2	
2005	40	37	15	6	2	
2006	41	36	15	**6**	**2**	
2007	42	35	14	**6**	**2**	

Physical Access to local NHS services

3.56 The Department publishes an extensive range of guidance for the planning and design of local healthcare facilities, including advice on the physical access requirements of buildings. The guidance is produced in consultation with relevant stakeholders, including disability groups, and takes account of statutory requirements such as the Disability Discrimination Act. In particular, Health Building Note 00-04: *Circulation and Communication Spaces* describes the critical dimensions of spaces – such as corridors, lobbies, staircases and lifts – that are required for the movement of ambulant and semi-ambulant people (including those using crutches, sticks and walking frames) and wheelchair users. Other guidance, such as those dealing with 'sanitary spaces' and 'Clinical and clinical support spaces', similarly contains guidance on designing an inclusive environment.

3.57 The Department's planning and design guidance is used by NHS Trusts and their professional and technical advisors in setting standards for the development of their capital investment schemes.

3.58 Disabled people are more likely to have difficulty accessing healthcare than other members of the general population. Disabled people face barriers through their reliance on public transport or assistance through family and carers or community travel. Low car ownership impacts on travel for medical appointments which could result in higher than average of 'did not attend' rates through missed or late notice cancellation of appointments by disabled people. Whilst these can increase costs for health and care providers, they risk increased health inequalities through later treatment and fewer opportunities for early intervention. This lack of transport means disabled people face multiple disadvantage, poorer health and disruption of treatment. This can limit the choice of treatment provider is restricted. This is reflected in patient experience of choice as reported through the patient choice survey.

Improving access isn't just about the physical

"Doctors need to give more time to people who need it and write down important points for those who may not be able to remember what was said".

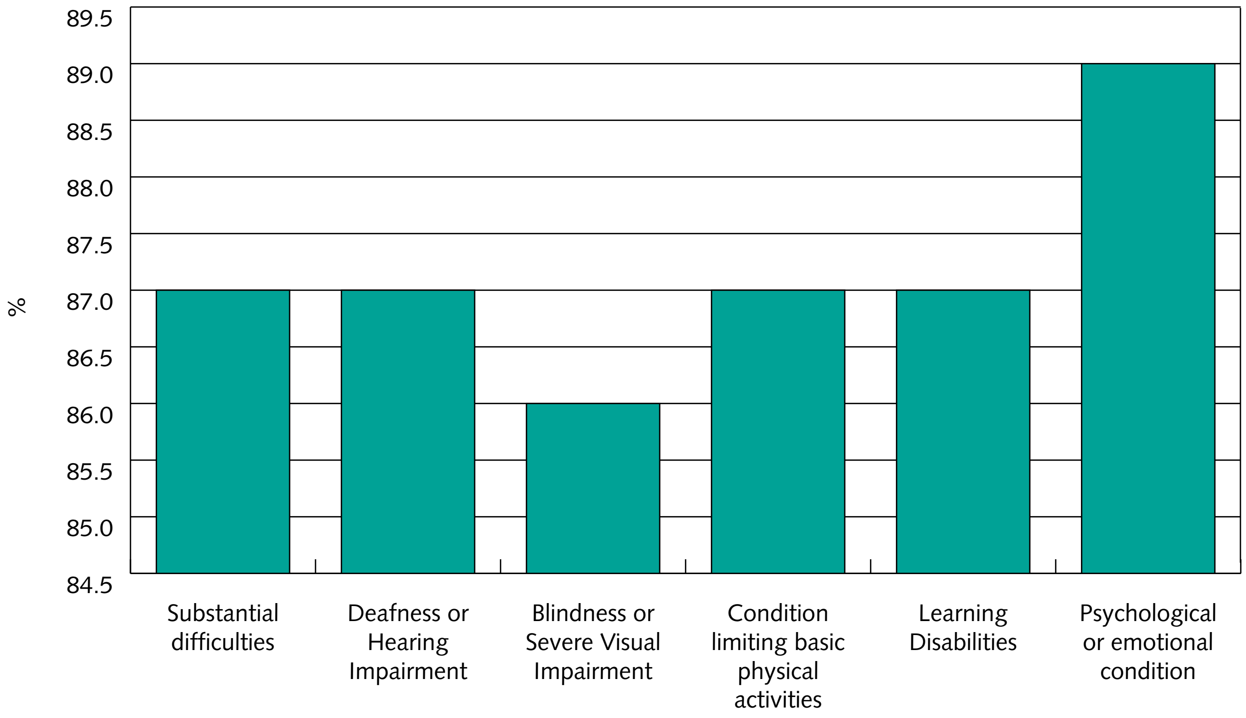
"Forms need to be made more accessible for people with learning difficulties to fill in and some may need extra support for this task".

Comments from disability equality stakeholder involvement workshop, January 2008.

Making information more accessible

3.59 The Office for Disability Issues (ODI) leads two programmes of work that will help improve information for disabled people. The Department of Health is fully involved in this work.

Specific GP – percentage able to book appointment with special requests



3.60 At the stakeholder event in October 2008 a repeated theme was concern about the accessibility of health and care sector websites and the degree to which they take account of the need for reasonable adjustment. The Health Informatics Review Equality Impact Assessment has reviewed research evidence to inform improvements in the accessibility to health sector information. The Review has been conducted with widespread consultation amongst staff, patients, carers and the public. It highlighted a number of improvements which could be made to sector websites.

- Be designed with semantic encoding in mind: if websites have been designed using headings to help the user scan for relevant information, this will aid the blind reader as well as the sighted
- Contain sensible use of the Alt tag to indicate the date that new content had been added rather than simply an icon marking as 'new'; this will be useful to both blind and sighted readers
- Be designed to encode meaning so that content can be easily converted and transferred to other devices. This will enable device independence, providing a greater range of I/O devices rather than adhering purely to QWERTY keyboard and VDU.

3.61 Information could then be delivered faster and more efficiently, enabling information to be more easily provided at point of care via small light mobile technology.

3.62 The Disability Rights Commission commissioned City University to undertake an analysis of five public access sites. Their report at http://www.drc-gb.org/publicationsandreports/report.asp made a number of recommendations. A key finding was that: '*…. if a site falls short of Level AA conformance, one or more impairment groups will find it difficult to gain access to its content*'. The Health Informatics Review Equality Impact Assessment suggests benefit in taking all sites to this level.

3.63 It is important that we do not simply focus on public access websites. Around 4% of the population works for the NHS. This work needs to cover information provided to staff so that sight-disabled employees can 'fully participate in employment (and education or make use of a service)'.

3.64 At present, the Department of Health website is compliant with Government guidelines and the commitment to improving government information for disabled people is set out in the 'images of disability' programme outlined in Chapter 2. The NHS position can be found via the NHS Web Identity Guidelines: (www.easyhealth.org.uk – this site is funded through the Department and offers easy read information).

Skills and capacity – raising awareness amongst staff

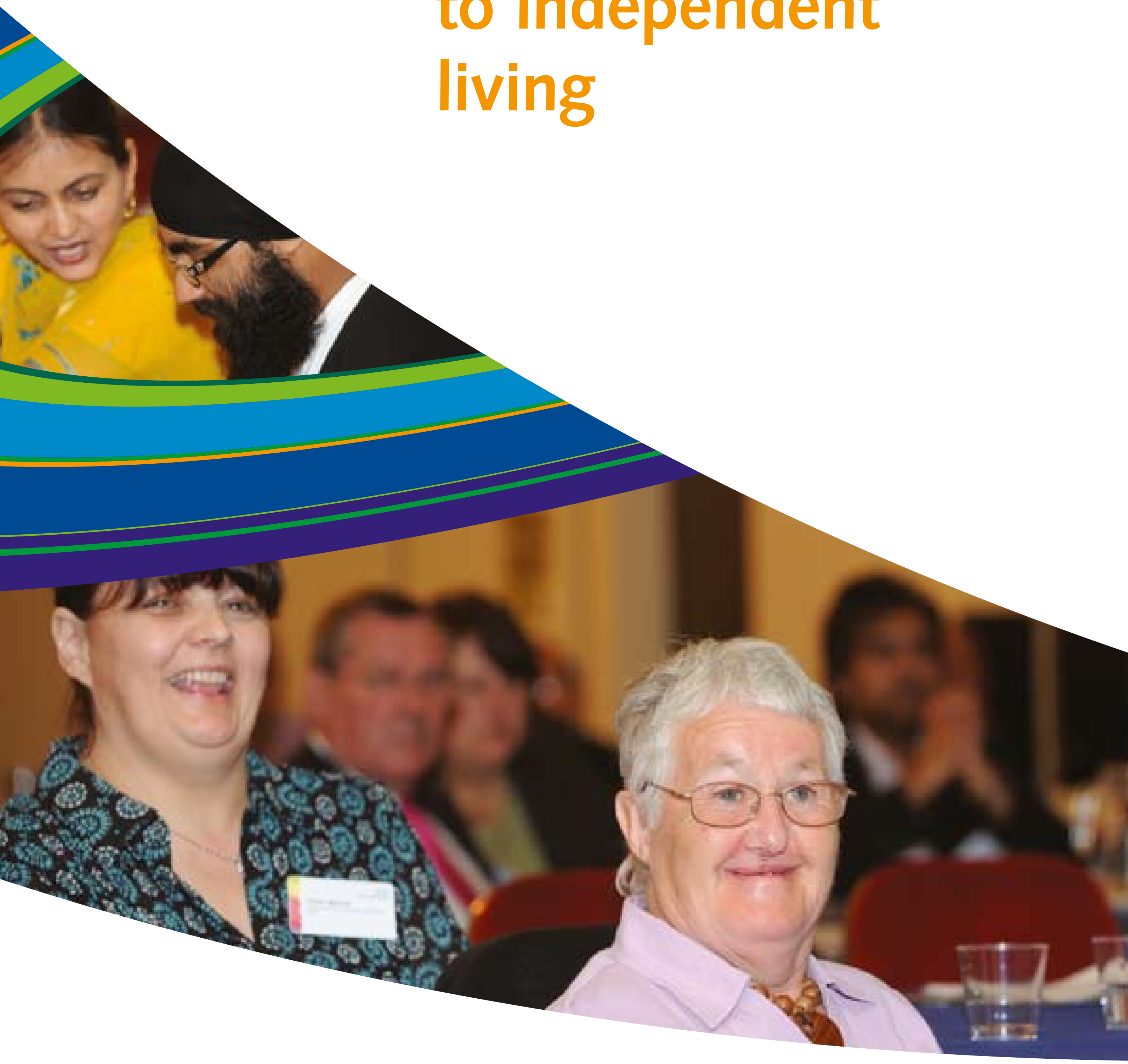
3.65 The *Dignity in Care* campaign was launched in November 2006 to create a zero tolerance attitude to lack of dignity in the care of older people in care settings. It encourages health and social care staff and stakeholders to work in partnership with a range of organisations who work with older people and those who care for them. There are now more than 1,800 dignity champions helping to ensure people cared for in the health and social care sector are treated with dignity and respect. Lack of dignity in care is not limited to older people. We aim to extend our work on dignity to all people who use health and social services, particularly disabled people.

Conclusions

- The Department is promoting a range of action to improve both access to general health services and the quality of health services for disabled people.
- There is a particular focus on improving the responsiveness of primary care services, which act as the gateway to the wider health system.
- Annual health checks should increasingly help to promote early identification of health risks for people with learning disabilities and people with severe mental health problems. Primary care trusts also need, however, more to ensure fast, convenient access to the wider range of healthcare services that will address the needs identified through annual health checks and other primary care consultations.
- There are well-documented instances of underperformance in the quality of healthcare provided for some disabled people, particularly people with learning disabilities. It is incumbent on Primary Care Trusts, healthcare providers and regulatory bodies to work together, in partnership with patient, family and carer groups, to drive up quality and provide more integrated services for disabled people.
- Coordinated work programmes are underway to address more systematically the improvements needed in commissioning, service quality, education and training, information systems, performance monitoring and regulation.

The next chapter looks at the health and social care sector contribution to helping disabled people live independent lives

Chapter 4:
Removing barriers to independent living



This Chapter outlines how we are supporting disabled people to live independent lives by:

- **Personalisation and planning that puts patients at the centre of care**
- **Greater choice for disabled adults, children and their parents**
- **Supporting user-led organisations, driven by closer involvement of carers and carer networks**
- **Personal budgets**

Introduction

4.1 Universal services are important to everyone, but they can have special significance for people with care and support needs. They may need different housing options, routes into employment, access to good quality health services.

4.2 Local authorities and their partners need to make sure that all services consider the particular needs of disabled people, older people and carers.

4.3 Disabled people are more likely to have difficulty accessing health care than non-disabled people. Barriers can be in the form of information as explored in the previous Chapter, or physical, for example difficulty accessing transport.

4.4 Negative attitudes marginalise citizens or groups. Attitudinal barriers can deny disabled people equal access to health and care services as well as social participation as equal citizens.

South West Strategic Health Authority have integrated their Single Equality Scheme with their (draft) Strategic Framework for the South West 2008/09-2010/11. This sets challenging targets for action on disability as part of its work on long term conditions

4.5 A lack of understanding among decision makers can contribute to behaviour that creates barriers to participation for disabled people. Nationally and in the health and care system, policy makers need to consider what knowledge they need to plan, fund and deliver services equitably.

Mrs Smith is a wheel chair user. She can use her electric wheelchair to get around without assistance, as long as:

- *the pavements allow*
- *the bus is accessible and is willing to wait whilst she gets on or off*
- *the counter at the advice centre is low and she can have a conversation with the customer officer*
- *there are accessible toilets for her*
- *there are good access ramps to shops or appropriate lifts*
- *she has access to the right kind of housing that is adapted for her wheelchair*
- *her employer has made the necessary adjustments for her to work.*

Without these adjustments, she can only get around with the help of an assistant – significantly limiting her independence and at a cost to the council.

Our considerations in determining progress:

What understanding is there of attitudinal barriers?

How is funding affecting the appropriateness of care for disabled people? Do we have financial incentives or additional barriers?

How are we involving disabled people and carers in taking decisions to ensure they retain a choice and control over the support provided by the health and social care system?

What action is being taken to support independent living for disabled people?

Overcoming attitudinal barriers

4.6 Launched in 2004 by the National Institute of Mental Health in England, SHIFT is a five-year Department of Health funded programme that tackles the stigma and discrimination associated with mental illness in England. A £600,000-a-year campaign led by the charities Mind and Rethink, has been extended to run until 2011. It will work alongside *Time to Change*[50], an £18 million campaign to tackle stigma and discrimination.

4.7 SHIFT acts as a bridge, linking the campaign into other well-being projects across Government. Its work complements *Time to Change*[50] by focusing principally on two areas: employment and the media. It will improve the coverage of mental health, and in particular challenge the link made between severe mental illness and violence.

4.8 Guidance on best practice for reporting mental health has been distributed to 10,000 journalists. It focuses on covering violence and suicide. The SHIFT Speakers Bureau, a bank of people willing to talk about their real life experiences of mental illness, has become an essential resource for journalists and a way of ensuring that people's voices are heard.

4.9 SHIFT is planning to fund a charity-run 'Stigma Watch' website to help people praise and complain about media coverage. It is supporting and coordinating efforts by mental health sector organisations including the Department, the charities, the Royal College of Psychiatrists and the NHS Confederation.

4.10 We published our draft Dementia Strategy in June 2008 and the responses demonstrated unanimous support of our proposed approach to develop a better awareness and understanding of dementia by the public and professionals alike. This includes breaking down attitudinal barriers and tackling stigma through better information.

Personalisation

4.11 The Government has set a clear direction for making personalisation, including a strategic shift towards early intervention and prevention, the cornerstone of public services. In social care, this means every person across the spectrum of need having choice and control over the shape of his or her support in the most appropriate setting. For some, exercising choice and control will require a significant level of assistance either through professionals or through independent advocates.

4.12 Across Government, reform of public services will mean that people are able to live their own lives as they wish, confident that services are of high quality, are safe and promote their own individual requirements for independence, well-being and dignity. Local priority setting will be focused on meeting local needs and playing a leading role in shaping strong and cohesive local communities.

4.13 Direct payments and individual budgets are an existing way to foster transformation in the community. Individual budgets (IBs), piloted in 13 local authorities, like direct payments, give people more choice and control. Individual Budgets can bring a number of income streams together to give the individual a more joined-up package of support. Critically they allow the person to plan how to achieve outcomes which meet their needs within a clear allocation of resources.

4.14 The Department of Health led the cross government initiative to pilot individual budgets from January 2006 to December 2007. An independent evaluation was conducted by a combined team of five university research units. It found that individual budgets had particular benefits for mental health service users and younger disabled people. While there were no important differences in overall cost, there were indications that individual budgets have the potential to offer greater value for money.

4.15 The evaluation found that Individual Budgets were generally welcomed by users because they gave them more control over their lives, but there were variations in outcomes between user groups. The Evaluation of the Individual Budgets Pilot Programme report was issued on 21 October 2008 http://www.dh.gov.uk/en/SocialCare/Socialcarereform/Personalisation/index.htm.

4.16 In the future, all individuals eligible for publicly-funded adult social care will have a personal budget (other than in circumstances where people require emergency access to provision); and a clear, upfront allocation of funding to enable them to make informed choices about how best to meet their needs, including their broader health and wellbeing. Having an understanding of what is available will enable people to use resources flexibly and innovatively. A person will be able to take all or part of their personal budget as a direct payment, to pay for their own support either by employing individuals themselves or purchasing support through an agency. Others may wish, once they have decided on their preferred care package, to have the council continue to pay for this directly. The approach, which may be a combination of both, will depend on what works best for them.

Using Individual Budgets

John, 35, used to dance and perform in theatre productions when he was young. He also drew portraits and designed logos for large companies. However since he became totally blind in both eyes, he said he feels isolated and depressed that he cannot access everyday activities.

Becoming more active, being independent and getting back into the community are steps John is taking to start rebuilding his life. He is using an individual budget (IB) to purchase an accessible mobile phone that will read out his text messages. It will help him stay in contact with friends and family and will help him feel safer about possible emergencies.

John has used his IB to employ a personal assistant who helps him with activities like going to the doctors and chemist, the cinema, gym, bowling and occasionally a football match. He also applied for an Assistive Technology grant to purchase a talking microwave and is using a direct payment, as part of his IB, to get domestic support for shopping, washing clothes, ironing, cleaning and gardening. In the future, John says he would like to gain further skills so he can return to some form of paid employment.

Personal Health Budgets

4.17 During the NHS Next Stage Review, there was a clear message from the NHS that the Department should build on the success of Individual Budgets in social care to increase personalisation of healthcare. Lord Darzi announced in his report, '*High Quality Care for All*'[23] that in 2009, we will pilot personal health budgets, as a way of giving patients greater control over the services they receive and the providers from which they receive services.

4.18 Personal health budgets can take a variety of forms and might cover part or all of a person's care and support package. This is just one of a range of mechanisms which aim to personalise NHS services, including care planning, the information prospectus and choice of provider.

4.19 Discussions have started on implementing the pilots and we are encouraging and facilitating the local and national involvement of user led organisations in developing further details. We will support people to share their experiences by creating an online learning community.

4.20 Together with the Department for Children, Schools and Families, we will pilot the Individual Budget approach before making any firm commitment to Individual Budgets for disabled children. A scoping study prior to the piloting was completed in July 2008 and the pilots are expected to start early in 2009. We see the introduction of Individual Budgets for families with disabled children as a possible means of ensuring that families are placed at the centre of the care planning process so they have choice and control over the services that are necessary and relevant to them.

4.21 This includes initiatives to ensure that parents with learning disabilities must have access to the same level of information and advice as all parents.

Integrating care through care packages

4.22 Personalised care packages enable patients with complex health and social care needs to move between the health and social care system without multiple registrations and barriers. This new model of care aims to empower patients and create prepared and proactive health and social care teams.

4.23 Care needs to be personalised and reflect the diversity of disabled people.
On review of the information available, there was a substantially higher average cost for ethnically diverse populations, which might reflect higher costs in urban areas or more specialised care packages, such as for language barriers.

Over 15 million people in England have a long term condition and this is expected to rise to almost 19 million over the next 25 years. People with long term conditions are very intensive users of healthcare services, accounting for 55% of all GP appointments and 77% of inpatient bed days.

DH estimate 2008

Sustaining co-operative working

4.24 Fair Access to Care Services (FACS) is a system to help local authorities set eligibility criteria for provision of services. The Fair Access to Care Services outlines a framework of four eligibility levels for supported services. These levels are set by councils and are based on assessed need. The levels correspond to increasing levels of risk if needs are not addressed: low, moderate, substantial and critical. An increase in the threshold in 2007-08 now means that some 73% of councils operate only at the highest two levels compared to 58% of councils in 2005-06.

The Commission for Social Care Inspection report *'The state of social care 2006-07'* raised concern about rising eligibility criteria. The report indicated shortfalls in care are particularly high in the population with moderate or low care needs. Only people with more serious needs are getting services.

4.25 In October 2008, the Commission for Social Care Inspection published their "State of social care 2006-07" report which provided a more detailed review of the Fair Access to Care Services framework and how it is being implemented by councils – *'Cutting the cake fairly: CSCI review of eligibility criteria for social care'*[14] highlighted the need for a fair and transparent allocation of resources through the implementation of eligibility criteria.

4.26 The Department of Health welcomes this report on the application by councils of the Fair Access to Care Guidance and its impact on disabled people, commissioned by the Minister for Care Services earlier this year. The Department will continue to support the democratic process within local government, to ensure that local councils are ultimately responsible for determining local priorities and allocating resources accordingly. We would not propose to make any short-term change to this whilst we engage in the longer-term debate over the future arrangements for the funding of social care.

4.27 To put service users and their family carers at the heart of what we do, it is necessary to have a transparent, open and fair system for the allocation of resources with a stronger focus on outcomes for people. Whilst the current Fair Access to Care Services Guidance goes some way in supporting this, the Commission for Social Care Inspection's review has highlighted the differing interpretations placed on it by councils. The Department therefore welcomes the recommendation that we should rework the Guidance to set it clearly in the framework of *'Putting People First'*[39]. This will offer councils an opportunity to spell out their policies clearly and in a way that people understand and experience as transparent and fair, and to use the resources available to them in the most effective way. We plan to work with key partners to revise the existing guidance and intend to consult on this in Spring 2009.

4.28 Councils in England operate at different eligibility levels. The average level in England is between moderate and substantial. This corresponds to the average council-supported provision of home care to about 42 per 1000 recipients over 65. Research shows that if all councils were to operate only at the critical or substantial level, the average provision of council-supported home care would fall by just under 20%. There would be a similar picture with supported care home provision.

4.29 The setting of thresholds and therefore the targeting of resources has had a significant effect on the level of non-residential services provided by councils, and particularly home care services. Since 1997, the numbers of households receiving supported home care has fallen from 479,000 to 358,000 in 2006. At the same time, the total number of hours of care has increased from 2.6 million to 3.7 million. The average hours per household in 2006 was 10.8 – double that of 1997.

Reform of the Care and Support system

4.30 The Government has also announced a Green Paper on the reform of the Care and Support system.

4.31 England is facing a major demographic change. By 2026, we expect the number of people over 85 to double, and there to be another 350,000 people aged 18-64 living with disabilities. In May 2008, the Department of Health launched a public engagement to raise awareness of the issues and to gather views from stakeholders and the public about how we should meet these challenges.

4.32 The six month public engagement on the future of Care and Support, was launched by the Prime Minister, to establish the principles for the Green Paper. It has been deliberately broad, involving both stakeholders and the public around the country. The Department has specifically aimed to involve and engage with key equality groups and their representative organisations. Where people have been unable to engage through the formal events, extra resource has been used to ensure that groups who are sometimes marginalised by a process of this sort have also been able to contribute their views.

Community care, cohesion and civic participation

4.33 The community in which people live can play an important role in the quality of their lives. For people with care and/or support needs it can play a much more significant part. Current service users and their carers can (and do) assist with the effective design of services for the future. In the process of working together they can add significant resources to each other through sharing experiences, sharing solutions and building friendships which contribute significantly to their well-being.

In the Tower Hamlets Linkage Plus Pilot where volunteering is a dominant feature of the project, older people are encouraged to take control of some of the services they use by participating in committees and fulfilling a range of volunteering roles in the network centres.

"Linkage also provides important organisational capacity building support to small self-help groups, to enable the volunteers who run the groups to access resources and provide more or better services. One such project has worked with a small group of older men. With the support of the outreach workers the group members constituted themselves as a registered charity and secured £5,000 from a charity… The model of a developing male self-help group is now being promoted to groups of men in different ethnic communities."

From Evaluation of the Tower Hamlets Linkage Plus Pilot

4.34 We are pursuing a number of initiatives for promoting this kind of engagement. We are working with the Department for Communities and Local Government (CLG) and Ministry of Justice (MoJ) on the local government empowerment agenda. We are also participating in the Communities and Local Government led cross-government activities on faith and cohesion. These include the production of standards for institutions engaging Muslim chaplains in public service.

Inclusive Volunteering Workshop Scope (at Nuffield Orthopaedic Centre) July 2008

The workshop focused on dispelling myths and misconceptions surrounding people with disabilities. It also examined the positive contribution that disabled people can make.

Attendees were encouraged to look at the language used when referring to people with disabilities; definitions of Disabilism and Disability; and medical and social models used when defining people with disabilities. The focus was on recognising that disability lies not with the individual but within society's inability to meet the needs of people with physical and mental impairment adequately. The workshop showed how it is within society's gift to empower people with disabilities by widening access to employment and volunteer opportunities. This can be done by:

- ensuring that advertising materials are available in a variety of formats: braille, large print etc
- ensuring that physical access to premises can accommodate individuals with varying levels of physical ability, specifically wheelchair users
- ensuring jobs are risk assessed and, where appropriate, modified so that people with disabilities have equal access to employment or volunteer opportunities
- providing a positive and supportive environment which empowers people with disabilities and allows them to contribute as valued members of society
- challenging negative and misguided attitudes toward people with disabilities within the workplace

Care packages for children

4.35 The *'Aiming High for Disabled Children'(AHDC)*[4] programme will improve support for all families with disabled children so they can live ordinary lives. The Department for Children, Schools and Families and Department of Health are responsible for implementing the programme. It was informed by the Treasury/ Department for Education and Skills *'Review of Children and Young People'*[41]. Evidence gathered through this review provided the rationale for focusing on specific service areas of the *'Aiming High for Disabled Children report'*.

Service areas:

Aiming High for Disabled Children includes the commitment by the Department for Children, Schools and Families of substantial sums to improve specific/priority services. Additional funding to improve health services for disabled children and young people has also been included in primary care trust baseline allocations including short breaks and implementation of the children's palliative care strategy.

- Wheelchairs and equipment
- Palliative & Continuing Care

System change measures:

Aiming High for Disabled Children is more than discrete funding pots. It covers whole system improvements through national expectation setting, performance management and user involvement:

- Core offer (building on existing National Service Framework 8) and indicator
- Improving data

Parents’ experience

4.36 A new indicator will assess parents’ experience of services for disabled children (aged 0 – 19). It will examine the extent to which services for disabled children are delivered according to the core offer standards: good provision of information; transparency in how the available levels of support are determined; integrated assessment; participation of disabled children and their families in local services; and accessible feedback and complaints procedures.

4.37 The new disability indicator will be based on a survey of parents and carers of disabled children. It will be a core part of performance management arrangements aimed at improving the quality of services for disabled children. This is a key priority of the Child Health and Well-Being Public Service Agreement.

4.38 Department of Health and Department for Children, Schools and Families have jointly developed a questionnaire and survey methodology to provide information on experience of services. We plan to measure a national baseline for the indicator based on a survey late in the 2008-09 financial year. The indicator will be measured at local area level from 2009-10. We are now in the process of identifying the research body to carry out the surveys.

4.39 The indicator forms part of the local government National Indicator Set and Vital Signs within the NHS Operating Framework. The more targeted interventions include learning disabled parents.

The ‘Core offer’ (for children and their families)

4.40 The core offer is a national statement of expectations based on five areas: information, transparency, participation, feedback and assessment. It underpins the development of the disability indicator, which will measure parental experience of services for disabled children through questions based around these core offer areas.

4.41 Through consultation events and circulation to local authorities and primary care trusts, Department of Health and Department for Children, Schools and Families we have received positive feedback on the core offer which we published in May 2008. We have also developed a set of materials to support local implementation. Our expectation is that local areas will take account of the core offer in developing and improving services for disabled children.

Improving access to continuing care

4.42 ‘Continuing care’ describes a package of health care, social care and education provided to children and young people in the community over an extended period because of disability, accident or illness. At present primary care trusts adopt their own method of deciding how they will meet a child’s needs. We are proposing a joint national framework with Department for Children Schools and Families for assessing a child’s need for continuing care. This will make the process consistent across the country and enable families to benchmark their own primary care trust against others. We launched the consultation on the framework in October 2008.

Supporting Independent Living for all

'Independent living' does not mean doing things for yourself, or living on your own. Instead, it means having choice and control over the assistance and/or equipment needed to go about your daily life; having equal access to housing, transport and mobility, health, employment and education and training opportunities.

Independent Living Strategy, Office for Disability Issues (ODI), March 2008

4.43 When it comes to supporting independent living, two of the most important enablers are information and advice. Both need to be easily available to help people navigate the complexity of modern public services. Local authorities are best placed to deliver this service.

4.44 Easy access is particularly important for:

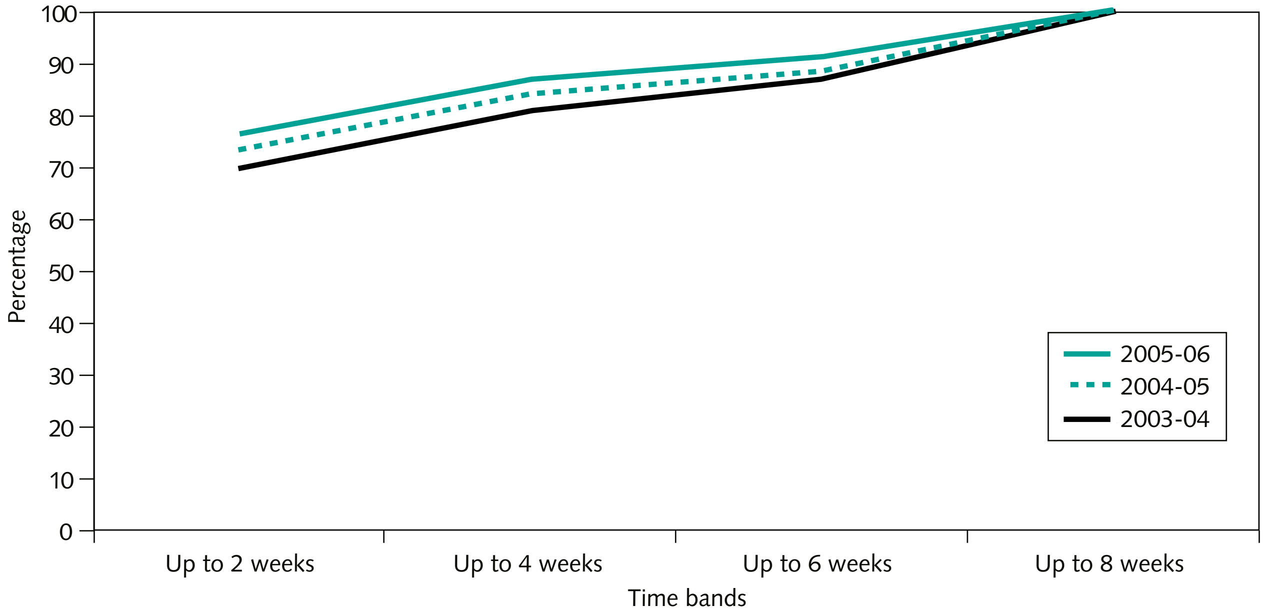
- state benefits, council tax rebates and housing benefit
- housing advice and housing options
- local knowledge about social and leisure activities including sport and exercise
- information about social care services and assisting people with their self-assessment of their care or support needs
- information for people taking on a caring role.

Evidence: Improving information supports access and therefore independence

"Forms need to be made more accessible for people with learning difficulties to fill in and some may need extra support for this task."

Comments from Disability Equality Stakeholder Involvement Workshop, January 2008.

Cumulative distribution of all new clients (aged 65 and over) for the completed assessment to receipt of all services in England, 2003-04[1] to 2005-06[2]



England									Thousands
	2003-2004			2004-2005			2005-2006		
Service	All ages	18-64	65 and over	All ages	18-64	65 and over	All ages	18-64	65 and over
Total number of clients receiving services	**1,737**	**482**	**1,254**	**1,720**[R]	**492**	**1,228**	**1,748**	**518**	**1,231**
Community-based services	**1,462**	**434**	**1,028**	**1,455**[R]	**444**[R]	**1,011**	**1,492**	**472**	**1,020**
Day care	267	115	153	242	107	135	243	108	136
Meals	200	13	186	176	11	165	165	10	155
Home Care	589	97	493	584	100	484	593	104	489
Overnight respite – not clients home	78	21	57	70[R]	21	50	68	19	49
Short term residential – not respite	53	11	42	63	13	50	64	12	51
Direct payments	15	11	4	24	17	7	37	25	13
Professional Support	389	183	207	420	204	217	442	215	227
Transport	61	23	38	63	24	39	..	..	..
Equipment and adaptations	481	107	374	479	102	377	499	112	386
Other	110	44	66	94	36	58	120	46	74
Residential Care									
Independent sector residential care	214	51	163	206	49	157	207	50	157
LA staffed residential care	39	5	34	38	6	32[R]	32	4	27
Nursing care	113	11	102	112	11	101	108	11	97

The figures for 2003-04 are estimates based on the figures from 149 P1 forms and 143 P2f forms
The figures for 2004-05 are estimates based on the figures from 150 P1 forms and 148 P2f forms
The figures for 2005-06 are estimates based on the figures from 150 P1 forms and 150 P2f forms

R = Revised data

Source: RAP Forms P18, P2f

Early intervention and prevention services

4.45 Early intervention and prevention services enable people to live with maximum independence, for as long as possible. Central to this idea is that everyone should be as independent as possible. Meeting the needs of all people means developing personalised services. Early intervention and prevention is important and also reduces demands on public provision.

4.46 Expanding access to screening programmes for cancer for older people has also been positive while a new prevention package for older people launched earlier this year will also do more on falls prevention, podiatry and audiology.

- The graph on page 63 shows there is still progress to be made in improving completion times for care assessments and receipt of services.
- The chart on page 64 shows numbers of service users and distribution of services provided.

4.47 Two important outcomes of prevention include:

- services that promote an overall sense of well-being, including social clubs, befriending services and practical help within the home. These are important in the quality of people's lives but there is currently little evidence to suggest that they will reduce demand on intensive health or social care services
- services that are more targeted on life events or long term conditions which can provide increased levels of independence and allow personalised approaches to be developed for those who have ongoing needs. These life events might include falls, dementia or complex health and social care needs.

4.48 The benefits of prevention services apply to everyone. These include:

- the right range of rehabilitation and recovery services that promote enablement and help people get back on their feet after specific events in their lives such as medical treatment, surgery or the death of a partner/loved one
- support for 'self care' where people with long term conditions help other people with similar conditions to better understand and manage their condition (e.g. the Expert Patients Programme). This approach is also helpful to carers
- support for people with mental health problems who may need therapy or supported routes into employment, education and other purposeful activities
- people with learning disabilities who need help accessing more independent housing, employment or other day activities and to equip those who can, to develop the skills for independent living such as transport training.

4.49 Home Improvement Agencies can make an important contribution to helping people remain in their own homes for longer, by ensuring the right physical adaptations to support daily living are in-place.

4.50 Supporting People services can play a central role in offering low-level support to help people moving on from a position of vulnerability and dependence on services towards independence. These include domestic violence hostels, homeless hostels, floating support for people recovering from mental ill health or drug/alcohol addictions. The Supporting People outcomes framework will be helpful to local authorities and their partners in judging which services focus on outcomes that deliver independence.

4.51 This will allow service users or their carers/advocates to:

- make their own arrangements for services with the money from the local authority
- get together with friends to make the arrangements together, or
- ask an agent or the council to make an arrangement for them.

Older People and Disability: Department of Health Campaigns Team – 'Dignity in Care'

The Dignity in Care campaign encouraged health and social care staff to work in partnership with a range of organisations that represent and work with older people and those who care for them. The campaign received several positive reports in Nursing Times January 2007 – an article about the number of elder abuse cases coming before the nursing regulator halving in the past year reported that *"nurses attributed the decrease in cases to new elder abuse awareness initiatives such as the Government's Dignity in Care campaign, launched last November"*. During 2007/08 the focus of the campaign was extended to include disabled groups.

Innovation in care

4.52 Our commitment to socially inclusive initiatives such as a '*National Dementia Strategy*'[30], recognises the importance of early diagnosis and appropriate choices rather than just action at times of crisis. This will require innovate approaches.

4.53 Our work so far has included developing:

- commissioning leadership within mental health trusts
- health and social care workforce
- a evidence and evaluation network with affiliated universities
- the *Communities of Influence* programme- which helps lay members and governors of NHS Foundation Trusts to supports inclusive outcomes.

4.54 Most recently we have created a team aimed specifically at developing and evaluating innovative practices. It is creating models in a range of different settings for others to learn from. These will be brought together and linked to the university network, ensuring this approach to transforming services at regional and local level remains sustainable.

4.55 We are working in partnership with the Department for Innovation, University and Skills (DIUS), the Engineering and Physical Sciences Research Council and the Economic and Social Research Council to sponsor the Technology Strategy Board. The Board has launched the '*Assisted Living Innovation Platform*'[5]. This aims to make significant advances in technology that enables people with chronic long-term conditions to live independently.

Involving service users and carers

4.56 Carers make a huge contribution to supporting individuals within their communities. We must develop services that also take their needs into account. Carers must be recognised for the work they do and be helped to lead a life outside their caring responsibilities.

An estimated 1.7 million disabled older people receive some level of informal care, plus an estimated 0.9 million younger people with physical sensory impairments or learning disabilities receive some level of informal care.

Overall, there were some 5.2 million people providing a level of care in England and Wales (in 2001); 10% of the total population.

4.57 Current service users and their carers can (and do) assist with the effective design of services for the future. They can also offer each other significant resources, through sharing experiences, solutions and building friendships which contribute significantly to their well-being. It is this kind of contribution that can drive the Government's target for a user-led organisation in every area by 2010.

User-led organisations

The Improving the Life Chances of Disabled People report recommended that by 2010, each local authority area should have a user-led organisation (ULO) modelled on existing Centres for Independent Living. User-led organisations are organisations led and controlled by disabled people.

The Department of Health has provided £750,000 in grants to 12 organisations across England over 2008-09 to become user-led Action and Learning Sites.

Some of the user-led organisations will use the grant to improve their business and organisational skills. It will also help them make links with – and get support from – local authorities and primary care trusts and other sources so they can act as a resource in the local area.

Investment in independent living

4.58 In some areas we have seen positive evidence that investment in independent living delivers better outcomes for disabled people. The personalisation agenda set out in '*Putting People First*'[39] involves additional investment to help transform the way social care is delivered. Housing adaptations can also have a positive impact on preventing hospital admissions and enabling people to continue to live in their own homes. To support this, disabled facilities grants have risen by 20% for 2008-09.

Your Guide to local services, being published by every primary care trusts, will include information on how people with long term conditions can obtain information and services to support selfcare. An **'information prescription'**, for example, will guide individuals to local support groups and useful resources to support independent healthy living.

Investing in care

4.59 Local authorities will use personal budgets to support parents with learning disabilities as part of their Transforming Social Care Strategies. More people will receive individual budgets and direct payments in order to increase their choice and control over where they choose to live. Individual budgets can give people more choice, flexibility and control over their personal care, as well as a better quality of life. They give people who have care needs the power to decide the nature of their own support and the report showed that most groups liked this.

Supporting Social Enterprise

Blackpool Tiggers is a recipient of Social Enterprise Investment Funding. The Blackpool Tiggers has around 70 volunteers providing a wide range of services, activities and support to people with autism and their families. This includes sports and physical activity, training on issues related to autism, holiday activities, IT skills, support for parents, partnership working with Relate and an outdoor gardening project. It has received the full endorsement of the National Autistic Society. The Department's investment is allowing Blackpool Tiggers to set up a new social enterprise 'My Town Tiggers' with the intention of helping people around the country start up their own autistic support groups using the Blackpool model through social franchising.

Investing in employment

4.60 For people with common mental health problems, there is increasing evidence that early intervention enables people to return to work and/or stay in work. The experience of the Department for Work and Pensions' '*Pathways to Work*'[36] programme, has suggested that Condition Management Programmes, one of the voluntary choices offering cognitive educational interventions to Incapacity Benefit claimants, aimed at helping individuals to understand and to manage their health conditions, can have a particularly beneficial effect. They help people to return to work, particularly when they have been on the Incapacity Benefit for less than 12 months. Meanwhile, it is equally important to provide better access to psychological treatments to help maintain people in work. This approach reduces the likelihood of the individual's need to seek the Incapacity Benefit and cuts employer organisation's sickness levels.

4.61 The whole approach to Incapacity Benefit is also changing. As part of the Government's proposals for welfare reform, the Department for Work and Pensions has introduced the '*Work Capability Assessment*' (WCA)[56]. This aims to create a more inclusive assessment of capability and health-related interventions. It will contribute to overcoming the health-related barriers that prevent disabled people, including people with mental health problems, from engaging in work.

4.62 We need to support those who want to and are able to work. A Work Focused Health Related Assessment (WFHRA) will therefore follow the Work Capability Assessment. Under the assessment, an individual will discuss work options, steps they can take to prepare for work and any relevant support needs. The assessment will be used by advisers and individuals to help develop an action plan.

4.63 The Individual Placement and Support (IPS) scheme also supports people into employment settings consistent with their abilities and interests based on a quick assessment of their skills and preferences. They can then develop their skills in the work environment while receiving ongoing support, this also provided to the employer if necessary.

4.64 We are working with the Department for Work and Pensions to ensure that the '*Pathways to Work*'[36] and '*Improving Access to Psychological Therapies*'[24] programmes are linked up. This co-ordination will allow individuals to take up the full range of support available. Back-to-work and healthcare support will be available as a single seamless package.

4.65 We are also working with the Department for Work and Pensions to fund an additional employment support element which will fit within the '*Improving Access to Psychological Therapies*'[24] programme. This pilot will ensure that people in this programme have early and easy access to employment advice. This reduces their risk of falling out of work and onto ill-health benefits.

Supported by the Department of Health's efficiency programme, local authorities have increasingly shown how developing homecare re-ablement services can support independent living and deliver value for money. Assistive technology such as telecare and minor adaptations, like fitting a handrail, can also enable people with support needs to continue to live in their own homes.

Health of the working age population

4.66 Dame Carol Black's wide ranging review of the health of the working population, '*Working for a Healthier Tomorrow*'[57], found that working age ill-health costs the country £100 billion a year, and that human costs to families are immeasurable. As a result, a coherent and strategic package of measures have been developed as part of a coordinated government response. Stakeholders will be heavily involved in aspects of this work and in concurrent work on the development of the National Strategy for Mental Health and Employment

4.67 The key initiatives announced in the Government response *Improving health and work: changing lives*[25] are below:

Creating new perspectives on health and work

A new electronic 'fit note' will be introduced across Britain in 2009
A new electronic 'fit note' will replace the current medical certificate, and help GPs switch the focus of their advice to what people can do rather than what they cannot. The changes will improve the flow of information between employers, individuals and GPs.

A National Education Programme for GPs will be rolled out across Britain from April 2009
This programme will improve GPs' knowledge, skills and confidence when dealing with health and work issues, and will enable them to adapt the advice they give to help people stay in or return to work

Health, Work and Well-being Coordinators, will be appointed for the English regions and Scotland and Wales from summer 2009
The Coordinators will stimulate action on health, work and wellbeing issues in their areas, offering advice and support to help local partnerships and engagement with smaller businesses in particular.

A National Centre for Working Age Health and Well-being will be established in late 2009
The Centre will form an independent, authoritative body providing a range of core functions related to the health and wellbeing of working-age people. These will include the gathering and analysis of data enabling the identification and monitoring of trends; and helping to determine the impact of interventions and initiatives. It will identify evidence gaps and encourage research to close those gaps.

Improving work and workplaces

The Business HealthCheck Tool
The Business HealthCheck tool will enable businesses to estimate the costs of sickness absence, turnover, worker ill-health and injury in their organisation; enable employers to identify the savings that could be generated by investing in health and wellbeing programmes; and help them measure the return on investment.

The NHS Plus Programme will be extended for a further three years
This expansion will allow NHS Plus to continue to work with others to further develop clinical and occupational health standards, and, to further test the most innovative ways of offering NHS Plus occupational health services cost-effectively to Small and Medium sized Enterprises.

An **occupational health helpline for smaller businesses w**ill be piloted from summer 2009
The development of an occupational health telephone helpline will offer help to smaller businesses by providing business hours access to professional occupational health advice on individual employee health issues (including mental health).

A challenge fund focused on supporting Small and Medium sized Enterprises will be available from summer 2009 *The challenge fund will encourage local initiatives that improve workplace health and well-being, through innovative approaches which ensure worker engagement.*

The National Strategy for Mental Health and Employment will be published in spring 2009
The Strategy aims to bring employment and health services closer together, support employers and healthcare professionals and tackle issues such as stigma and discrimination.

A review of the health and well-being of the NHS workforce will be commissioned
This review of the NHS workforce will consider the evidence for where the priorities for whole-system improvement should be and recommend action that will enable local delivery.

Supporting people to work

Piloting early intervention services
A range of **early intervention services including the Fit for Work service will be piloted** in 2009 and run until at least 2011. These will include: ‘Fit for Work’ service pilots; the embedding of Employment Advisers within the Improving Access to Psychological Therapies (IAPT) programme from early 2009; and the extension of the Pathways Advisory Service, which places Employment Advisers in GP surgeries, for a further three years.

The early intervention services will support individuals by making access to work-related health support more widely available. The 'Fit for Work' service pilots will provide case-managed, multi-disciplinary support and various models will be tested. All pilots will be comprehensively evaluated.

The Access to Work programme will be extended

The changes to Access to Work will improve effectiveness – making the service as flexible and timely as possible and reaching more of the people who need it, particularly those who have fluctuating conditions.

Conclusions

- Personalisation will give disabled people choice and control over the support they receive;
- Attitudes are a key barrier for disabled people but steps can be taken to address these;
- We are removing barriers to independent living through investing in care services and providing greater choice through personal budgets for disabled people;
- Service users and carers are assisting with the design of services for the future;
- Increasing work opportunities for disabled people is a key aspect of supporting people to live independently.

The next chapter looks at the progress of disabled people in the health and care services workforce.

Chapter 5: Towards a healthy, resilient, productive and diverse workforce in the NHS and Social Care Services

This Chapter covers what we are doing to:

- **Improve workforce data, enabling us to identify trends better**
- **Improve the representation of disabled people in the NHS and Social Care**
- **Improve staff training, ensuring the entire workforce is aware of the Disability Equality Duty, requiring all staff to treat all patients with dignity and respect**

Introduction

5.1 Health and care services touch the lives of everyone in England in some way. The sector workforce should reflect the diversity of the population it serves. We need better data to monitor the make-up of the workforce and take action where there is under-representation of minority groups, including disabled people. We need to open up opportunities at every level and support disabled people in the workplace. We also need to ensure that the whole workforce is supported through awareness training and education to respond to the diverse needs of disabled people.

Our considerations in determining progress:

What information is available about disabled people employed across the NHS workforce?

What progress is being made by disabled people in leadership positions in Department of Health arms length bodies and the NHS?

What support is being provided to disabled people in the NHS workforce (including reasonable adjustments)?

Workforce profile and employment information

5.2 Since April 2008, the Electronic Staff Record provides HR and Payroll services to 586 organisations and over 1.3m employees. From 2010 it will be the main source of NHS workforce data, providing us with better information to identify trends and target action where improvement is needed.

5.3 For the purposes of this report, any NHS workforce information included is taken from the NHS staff survey.

Representation of disabled people at NHS Board level

5.4 As shown in the following table, data collated on NHS Board appointments show that an average of 4.24% of local and national board members were disabled people. Non-executive appointments have a consistently higher representation of disabled people at local level than those at national level Department of Health-related board appointments with the highest proportion of disabled board members appointed are in primary care trusts.

5.5 This information also gives an indication of the level of 'civic participation' as measured through PSA 21 *(Build more cohesive, empowered and active communities)*.

Appointments Commission role

5.6 The Appointments Commission acts as a key driver of equality. One of its six strategic objectives is: *"to promote public appointment opportunities and to strengthen the candidate*

National DH Related Board Appointments. People in post at 30/06/2008

	All Members	Women	Women %	BME	BME %	Disability	Disability%
Chairs	57	12	21.05	2	3.51	0	0.00
Non-Executives	830	344	41.45	96	11.57	32	3.86
All Members	887	356	40.14	98	11.05	32	3.61

Local NHS Board Appointments. People in post at 30/06/2008

	All Members	Women	Women %	BME	BME %	Disability	Disability%
Chairs	297	90	30.30	23	7.74	10	3.37
Non-Executives	1671	598	35.79	206	12.33	79	4.73
All Members	1968	688	34.96	229	11.64	89	4.52

PCT Appointments. People in post at 30/06/2008

	All Members	Women	Women %	BME	BME %	Disability	Disability%
Chairs	150	52	34.67	18	12.00	7	4.67
Non-Executives	909	342	37.62	128	14.08	47	5.17
All Members	1059	394	37.20	146	13.79	54	5.10

ALL Appointments (Local and National Combined) Appointments. People in post at 30/06/2008

	All Members	Women	Women %	BME	BME %	Disability	Disability%
Chairs	354	102	28.81	25	7.06	10	2.82
Non-Executives	2501	942	37.66	302	12.08	111	4.44
All Members	2855	1044	36.57	327	11.45	121	4.24

Arms Length Bodies

National DH Related Board Appointments. People in post at 30/06/2008

	All Members	Women	Women %	BME	BME %	Disability	Disability%
Chairs	57	12	21.05	2	3.51	0	0.00
Non-Executives	830	344	41.45	96	11.57	32	3.86
All Members	887	356	40.14	98	11.05	32	3.61

pool, ensuring applications from diverse backgrounds". Attracting disabled people as candidates, however, remains difficult. We are also continuing to see a reduction in the percentage of women servicing on boards in the NHS. The proportion of people from black and minority ethnic backgrounds, however, is being maintained.

A number of initiatives are underway to improve the diversity of applicants such as:

Strictly Boardroom advertising campaign, working with Race for Health programme with Manchester Primary Care Trusts to encourage disabled people and people from black and minority ethnic communities to apply for non-executive directorships in their local NHS.

5.7 Work is also underway in partnership with NHS Employers, the employer arm of the NHS Confederation. As members of the Employers Forum on Disability (EfD), NHS Employers can access a much wider pool of expertise than that available to individual trusts. Through its annual benchmarking survey, NHS Employers can encourage NHS organisations to improve standards. The work promotes the benefits of involvement across the sector, helping to drive up standards and increase overall compliance with the Standards for Better Health and successor measures.

Opening up employment opportunities

5.8 The strategic health authority equality leads network provides support to the delivery of greater employment opportunities for people with mental health conditions and learning disabled people.

5.9 Through the Department of Health NHS Change Programme (Pacesetters Wave 3) we are working with a small number of NHS organisations to develop innovative ways of helping people with mental health and learning disabilities into paid NHS employment. We will disseminate the results through the strategic health authority network.

Building skills and understanding

5.10 To make long-term changes a significant cultural shift is needed. We therefore need a clear commitment from leaders at all levels of the health and care sector to appropriate staff training. We will promote examples of good practice from exemplar employers to secure NHS engagement.

5.11 Initiatives include programmes to ensure that staff working with learning disabled people receive learning disability awareness training from service users and family carers. In addition, we will work with Skills for Care to develop four new knowledge sets by March 2009. By early 2010, new qualifications focused on disability should be in place.

5.12 The Disability Rights Commission report *'Closing the Gap'*[19] raised issues about the need to promote employment opportunities for disabled people. NHS Employers is working with the Employers Forum on Disability and Job Centre Plus to explore how to increase the employment, work experience and volunteering opportunities for people with learning and mental health disabilities within the NHS.

5.13 More specifically, NHS Employers has been working closely with the General Medical Council and the Nursing and Midwifery Council on their *fitness to practice* issues and access to training. NHS Employers has given evidence to inquiries and attended advisory groups designed to assist them in working through the specific issues of increasing access and removing barriers for disabled people.

5.14 With the Disability Rights Commission we have published *'A National Framework for Disability Equality and Etiquette Learning'* (DEEL) for health and social care services. In addition, we are developing with the Royal Colleges a *'Treat me right'*[52] leaflet on how to work with people with learning disabilities. We have also launched a joint programme with the Equality and Human Rights Commission (EHRC) to embed learning disability and human rights in undergraduate curricula.

Partnership working for employment opportunities

5.15 In partnership with the Department for Work and Pensions and Job Centre Plus we are looking at ways of using Access to Work

Department of Health Commitment from the Independent Living Strategy

Education and awareness programme for National Health Service staff on increasing choice and control and on the Disability Equality Duty

The Department of Health will design and deliver an overarching national awareness and education programme on the Disability Equality Duty for National Health Service (NHS) organisations, including clinical and non clinical staff working at all levels within and across the NHS. This includes the Department of Health, Care Services Improvement Partnership (CSIP) and the NHS confederation at a national level, Government Offices for the Regions, Strategic Health Authorities and regional co-ordinators of CSIP, and Primary Care Trusts (PCTs), Foundation/other Hospital Trusts and Mental Health Trusts at a local level.

The programme will consist of three key elements:

- an overview publication that sets out the critical themes and messages from the recent Disability Rights Commission Formal Investigation into Healthcare; and a summary of common themes and issues arising from the recent performance of the NHS on implementing their Disability Equality Duty schemes. A focus on particular barriers experienced by specific groups of disabled people will feature in this overview publication (for example, disabled people from black and minority ethnic communities, people with learning disabilities, people of all ages with mental health support needs, older disabled people, people with multiple sensory impairments, and people with communication support needs)
- an explanation, in the form of a guide for disabled people, and NHS staff about what choice and control means for disabled people of all ages with respect to accessing and using NHS services and facilities. This would set out the role of the NHS and others, (for example, user and peer-led organisations), in enabling and supporting disabled people to maintain their health and wellbeing. This guide would include a specific focus on black and minority ethnic disabled people
- scoping and profiling good practice in equal access to healthcare and health support; and in supporting disabled people to maintain their own health. This good practice guidance will be produced in partnership with disabled people and their organisations, including black and minority ethnic disabled people and other relevant organisations.

funding to secure the engagement of local employers in developing opportunities for disabled people.

5.16 NHS Employers are also working in partnership with the Department of Health to improve occupational health provision in the NHS and their initiatives to support people with health problems remaining in or returning to work.

Working to achieve PSA 16

5.17 To increase the opportunities for adults with learning difficulties, regional employment teams on mental health will link their work programme to the PSA16 workstream.

5.18 The Life Chances Cabinet Sub-Committee has asked us to find ways of increasing the number of adults with mental health problems and learning disabilities employed in the NHS. We are working with a number of partner organisations to identify programmes that might support local NHS employer engagement, for example Local Employment Partnerships and Access to Work, which are run by Job Centre Plus.

5.19 In addition, we have agreed a programme of work with NHS Employers that includes publication of refreshed guidance on mental health and employment.

Making reasonable adjustments in the workplace

5.20 Workplace assessments are available for all health sector staff (including those without ‘declared’ physical impairment). Adaptable screens and speech readers are available to the visually impaired.

5.21 All new NHS buildings will be fully accessible for physically disabled people – contracts for LIFT/Private Finance Initiative state reasonable adjustments are to be made; these are not just physical, and appropriate methods for providing access to information need to be considered.

Conclusions

- There has been progress made in improving workforce data and work continues to further improve this;
- Action is underway to improve staff training and development. This will ensure all NHS staff:
  - understand the principles of achieving independence, of choice and control for the service users;
  - see the importance of working in partnership with carers – including treating them as expert care partners;
  - respect the dignity with which all people should be treated;
- There has been good work to open up employment or volunteering opportunities;
- Progress has been made in making ‘reasonable adjustments’ in the NHS workplace where these are needed. We will build on this work to:
  - Monitor our performance in increasing employment opportunities for disabled people at every level
  - Further improve awareness and education.

The next Chapter outlines the progress being made by disabled people in the Department of Health workforce.

Chapter 6: Towards a healthy, resilient, productive and diverse workforce in the Department of Health

This chapter describes the action Department of Health is taking to:

- **increase the represenation of disabled people in the Department and Arms Length Bodies**
- **improve workforce data, enabling us to identify trends better**
- **improve staff awareness of disability equality**

Introduction

6.1 In 2005, the Cabinet Office launched *'Delivering a Diverse Civil Service: A 10 Point Plan'*[16]. Its purpose was to push our commitment to diversity over the three years to 2008. It was an ambitious plan at the centre of Civil Service reform aimed at helping us to achieve a more diverse workforce. We needed to become better equipped to deliver, adapt and innovate and we have made progress, but we cannot be complacent.

6.2 *'Promoting Equality, Valuing Diversity – A Strategy for the Civil Service'*[38] builds on what we have already achieved. It reflects the expansion of mainstream equality and diversity into every aspect of our work. It is also a framework of commitments that will help us fulfil our new single public equality duty under the Government's new vision for equality, *'Framework for a Fairer Future- The Equality Bill'*[21].

Our considerations in determining progress:

How well the Department is performing against Cabinet Office and its own stretch targets for employee diversity?

How disabled staff are progressing in their Department of Health careers?

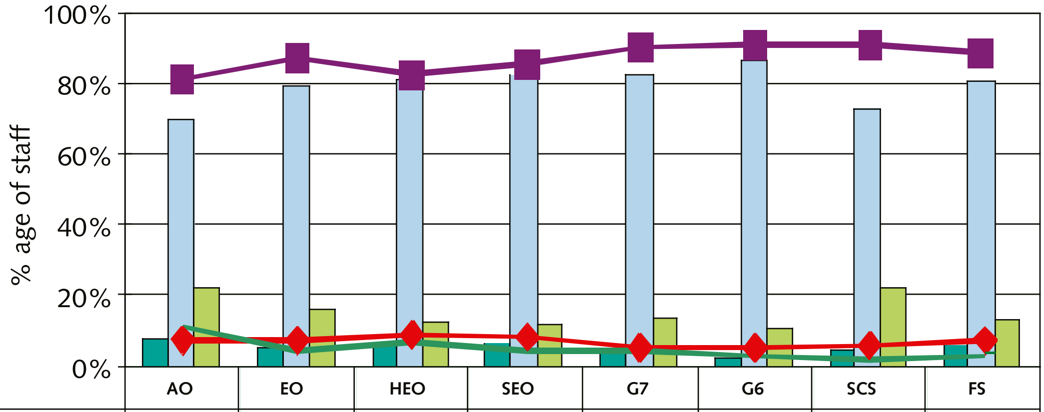
What support is available to improve both the culture and diversity of the workforce?

What further activities are planned to help disabled staff progress?

6.3 Between June 2007 and June 2008 the number of disabled staff in the Department of Health increased by 2% (48) and the number of non-disabled staff increased by 8% (163). As the Department had already reached Cabinet Office targets, more stretching targets have been set for delivery by 2011.

Progress in the Department

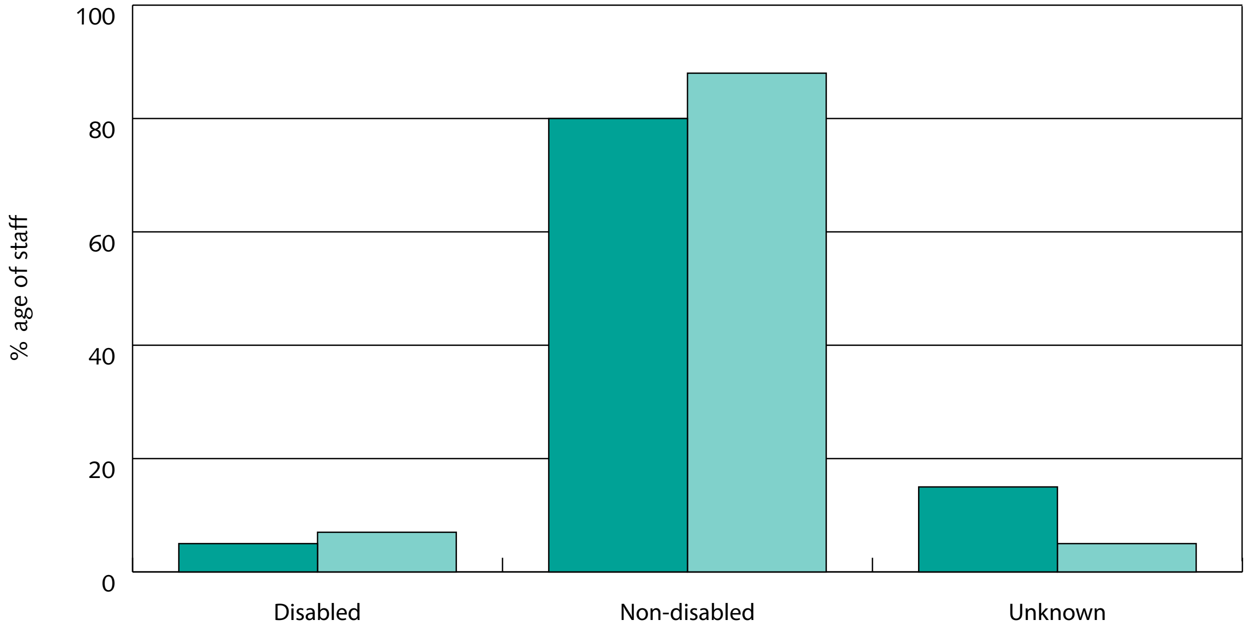
Disability by grade



	AO	EO	HEO	SEO	G7	G6	SCS	FS
Disabled (June 07)	8%	5%	6%	6%	4%	2%	4%	6%
Non-disabled (June 07)	70%	79%	81%	83%	82%	87%	73%	81%
Unknown (June 07)	22%	16%	12%	11%	14%	11%	22%	13%
Disabled (June 08)	8%	8%	10%	9%	5%	5%	6%	8%
Non-disabled (June 08)	81%	88%	83%	86%	91%	92%	92%	89%
Unknown (June 08)	11%	4%	7%	5%	4%	3%	2%	3%

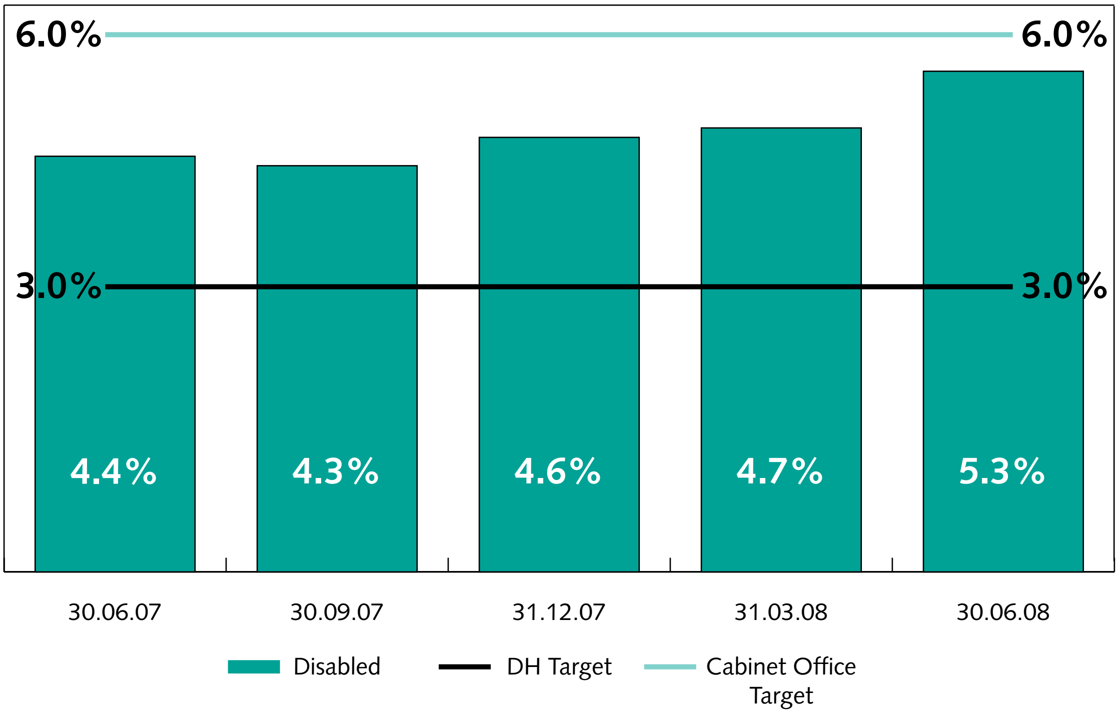
Grades: AO Admin Officer; EO Executive Officer; HEO Higher Executive Officer;
SEO Senior Executive Officer; G7 Grade 7 (Principal); G6 Grade 6 (Senior Principal);
SCS Senior Civil Servant; FS Fast Stream (Graduate entry)

Annual comparison



With concerted effort, we have increased self-reporting by staff, at end June 2008 we held disability information on 95% of the 2114 staff members. This represented an increase in reporting of 10% (223).

SCS disability against targets



Opportunities for staff involvement

6.4 One of the main ways staff within the Department are involved in developing action to achieve these targets is through staff groups aligned to the equality strands. EnABLE is a self-organised group that provides support to disabled staff. It is involved in the development and review of internal policies and initiatives, and is a key stakeholder in the Equality Impact Assessment of those policies. The Department will continue to support the role and function of this network and will reconsider the role of all equality staff stakeholder groups as part of the wider equality stakeholder review taking place to March 2009.

Disability (Single) Equality Scheme workforce themes

6.5 The Department's Disability Equality Scheme (which forms part of the Single Equality Scheme) sets out the commitments and actions that underpin the overall goal of improving the representation of disabled people in the workforce. These have been shaped by statistical data, consultation with the staff network for disability, and the conclusions from a qualitative research project that examined the barriers to career progression for disabled staff. The main themes for staff with disabilities include:

- the need for strengthened governance in respect of the diversity agenda;
- awareness raising training for all staff, starting with senior managers;
- a programme of review for all relevant HR policies and guidance, to ensure compliance with the Disability Discrimination Act and good practice; and
- the appointment of a senior level Champion for disability issues.

Measuring our progress

6.6 The key measures for the Department are:

- a commitment to improving the representation of disabled staff at senior levels. We have set a target of 6% (currently 5%), to be achieved by the end of March 2011. This is higher than the target of 5.2% set by the Cabinet Office for all government departments.
- From June 2007 to June 2008, of the people (92% of staff) who responded to the question 'Do you consider yourself to have a disability?', the declaration rate on disability rose from 4.92% to 7.2%. Our target is to achieve year on year increases, reaching 10.9% (the percentage of the economically active population by the end of March 2011 (Source: Cabinet Office, 2008)).
- during Quarter 1 3% of the average workforce (63 people) exited the Department. The main reason for leaving continues to be resignation. 67% (43) of the disability profile was known. 14% (9) of those who left had a disability.
- of the 28 people in the Priority Posting Pool (PPP), 8 (29%) were posted over the last quarter. Of the 3 (11%) disabled staff in the PPP, none were appointed.
- during Quarter 1, 153 posts were advertised on FJSS (Internal Recruitment), 3% (4) at AO, 18% (28) at EO, 16% (25) at HEO, 20% (31) at SEO, 33% (51) at G7 and 9% (14) at G6. 21 posts were filled through FJSS, 65 posts advertised received no applicants. 75% of applicants had known information on disability. Only 6% (7) of applicants were disabled; 57% (4) were interviewed; and 2 of the 4 (50%) were appointed.
- of those who applied for internal promotion, 6% (3) were disabled. None were subsequently promoted.
- during Quarter 1 there were a total of 4 grievances (0.18% of the total workforce) and there were 5 disciplinary cases (0.23% of the total workforce). 25% (1) grievance was raised by someone with a disability and 60% (3) cases were against staff with a disability.
- of the 331 staff who appied to attend a corporate training course, 265 (80%) attended the course. Of those who applied for training, only 4% (14) were disabled. All attended the training.
- the 2008 staff survey satisfaction ratings for staff with (declared) disabilities were less positive than the ratings for non-disabled staff for most questions. In response to the question 'I can look to my line manager as a good role model', only 39% of disabled staff agreed – compared with 66% for non-disabled staff. We aim for year-on-year improvements in satisfaction ratings.
- following the introduction of a new HR management information system this year, we will analyse exit interview data by disability when there is a sufficient body of evidence to generate meaningful data (Summer 2009).
- Equality Impact Assessments are carried out for all HR policies to ensure there is a neutral impact for staff with disabilities, and the potential for positive impact.

Department of Health Values

6.7 We are committed to embedding the Department's values and behaviours in all areas of business. We believe this will help maximise potential in *all* staff. As all staff should be aware in the Department:

- *We value people – we care about people and put their health and wellbeing at the heart of everything we do*
- *We value purpose – we focus on actions and decisions to achieve our shared goals*

- *We value working together – we work as one department and with our partners and stakeholders*

We value accountability – we take responsibility and are open to challenge.

Disability Equality Scheme

6.8 The progress of embedding these values is driven by a broad spectrum of activities, ranging from those that promote organisation-wide culture change to specific and tangible support for individuals. For example, we are developing an equality e-learning tool, to raise awareness of the legislative requirements, including disability and other equality legislation, and help promote the desired behaviours and attitudes. All staff, including senior managers, will be required to use the tool.

6.9 We have introduced a bullying and harassment policy, supported by anti-bullying and harassment workshops, using case studies based on the experiences of Department of Health staff.

6.10 A mental wellbeing strategy and policy launched in October 2008. As part of this, we will be piloting a mental health awareness workshop ('Beyond Blue') which has received endorsement from Dame Carol Black and SHIFT.

6.11 We have a range of policies and services in place that support staff with disabilities. These include: guidance on home-based and flexible working; 'reasonable adjustment' provisions built into the Sickness Absence policy (which enable disabled people to join the Department of Health or current employees to remain in work); workplace assessments, which conform to Health and Safety Executive standards; Occupational Health provision; and an independent, confidential counselling and welfare service.

6.12 Accountability for the delivery of the equality and diversity agenda is built into business planning and the performance management process for senior managers. There is now a senior level Disability Champion who is a member of the Corporate Management Board.

6.13 In recruitment we use the two-tick symbol and positive action statements in all relevant literature and the guaranteed interview scheme is open to all disabled applicants who fulfil the minimum person specification requirements. In Autumn 2008 we will also launch a new approach to selection exercises for promotion. This approach addresses many of the concerns raised by the disabled staff who participated in the 'Barriers to Career Progression' research project.

Providing a healthy work environment

6.14 To ensure these policies take root, we are working hard to nurture a positive work environment. To that end, the Department published its health and wellbeing strategy in October 2008. Developed in consultation with specialist external bodies, it makes clear that what may assist the health and wellbeing of one member of staff may not another. We do not anticipate any negative impact for staff who consider themselves disabled. However, as part of the initiative we are considering providing extra gym sessions, which cater for the needs of staff with certain disabilities such as visual impairments and certain long term conditions.

6.15 We are also piloting how best to improve the health and wellbeing of all our staff with initial testing focusing on the Health Improvement and Protection Directorate:

'Healthy HIP'. This includes focused workshops (eg physical activity, nutrition, working behaviours), team and individual physical activity challenges and using the 'Workplace Champions Model' to motivate staff to take ownership of this important agenda.

Diversity profiles and monitoring

6.16 In the wider context, we are now using the social model of disability for diversity monitoring. In its representation of disabled staff, the Department of Health compares favourably with other government departments. However, we are looking to increase the numbers and reduce the number of staff (currently 8% in the Department) who have not declared themselves as disabled or non-disabled.

6.17 The activities we monitor by disability currently covers;

- staff in post
- applicants for employment
- applicants for promotion
- applicants who pass/fail the paper sift
- appointments to posts
- progress against targets to increase the number of women, BME and disabled staff in the senior civil service
- staff who apply for, and receive, training (central training programme)
- staff involved in the grievance procedure
- staff subject to disciplinary procedures
- staff leaving Department of Health, and
- staff who benefit or suffer detriment as a result of the Department's performance assessment procedures (in particular, black and minority ethnic staff – as required by the race equality duty).

Underpinning evidence

6.18 The new Civil Service Diversity strategy sets out the key requirements for all government departments. One of the main themes is improving the representation of disabled staff at all levels in the organisation. The other themes are more generic in nature but create the environment in which more specific initiatives can have the maximum effect. Specifically;

- *Changing behaviour to create a more inclusive culture*. This will be assessed through the improvements in satisfaction ratings in quarterly staff surveys
- *Talent management systems that enable everyone to reach their potential.* We will actively encourage participation from disabled staff in the Department of Health Talent Development Programme; assess the diversity make-up of those who apply and are selected; and track progress – by diversity profiles – of those who graduate from the Programme.
- *Strong leadership down to first management level and clear transparent accountability for delivering diversity.* We have developed guidance for the senior civil service on setting diversity objectives, which will strengthen responsibility and accountability at this level.

Conclusions

- Although there has been considerable progress in identifying and tackling the barriers to improved disability equality for employees of the Department of Health, there is still much to do.
- Increasing the involvement of people with disabilities in policy development, and raising capability and capacity to do this are being prioritised through the Single Equality Scheme.

- Actions that are already being undertaken are an increase in targeted support, coaching and mentoring opportunities for staff with disabilities, and a prioritised programme of Equality Impact Assessments of Human Resource policies, with the involvement of the Department of Health's diversity networks.
- Greater flexibility on how people do their jobs is being promoted, and more support offered to line managers on managing a diverse workforce with particular focus on 'reasonable adjustments'.
- The programme of activity will be monitored on a quarterly basis by the HR senior management team and at an organisational level through the governance arrangements put in place for monitoring progress against the Single Equality Scheme actions.

Further research will be commissioned to support the organisation's action plans, for example a review of the wording of the appointment criteria, to identify whether changes would help to encourage more diverse applications without diminishing the calibre of appointments made.

The next Chapter outlines the approach taken to evidencing this report.

Chapter 7: Producing the evidence

This chapter briefly outlines the processes undertaken to gather the evidence to support this report.

Introduction

7.1 The evidence that supports this report comes from a range of sources. These included; data analysis and synthesis; desk research of qualitative information (including sector specific reports and information on Disability Equality Schemes across the sector); one-to-one discussions with disabled people (around the report focus); use of a specific stakeholder steering group information (including NHS representatives); discussions with SHA Equality Leads; and reviews of good practice from across the sector.

The Process

7.2 During this report we used the following stages to gather information;

- initial commission, call for evidence and good practice
- establishment of steering group
- review of good practice and identified data sets
- desk review of key documentation
- identification of key themes and gap analysis
- mapping of progress
- further data identification and analysis
- review of current evidence
- consultation and face to face discussion with stakeholders

The report journey

7.3 The report sets out the key elements of the journey through the health and social care system. We used evidence of how discrimination is being tackled and disability equality positively promoted through policy making activities within the Department of Health, its arms length bodies and across the health and care sector.

7.4 Access to and Integrated care

Supported by:

- Review of Public Service Agreements
- Desk/literature review of reports on the sector
- Review of Equality Impact Assessments on central file
- Individual discussions with report steering group members (includes analysts from Social Care Directorate)
- Individual dialogue and contributions from key policy managers
- Individual discussions Information Centre officials and Departmental Knowledge and Intelligence analysts
- Review of action plan monitoring and progress (Promoting Equality Steering Group)
- GP Patient Satisfaction and Choice Survey (Information Centre)
- Healthcare Commission annual health check
- UNIFY (Department of Health web-based database containing Vital Sign indicator performance by NHS organisations)

7.5 Removing barriers to independent living

Supported by:

- Review of Public Service Agreements
- Desk/literature review of reports on the sector

- Individual discussions with report steering group members
- Individual dialogue and contributions from Social Care, Local Government and Care Packages Group (independent living, local government, mental health policy)
- RAP: Referrals, Assessments and Packages data
- SR1: Supported Residents data, and
- Commission for Social Care Inspection: The State of Social Care 2006-07
- UNIFY (Department of Health web-based database containing Vital Sign)

7.6 A diverse workforce – the NHS and Social Care

Supported by:

- Review of Public Service Agreements
- Review of Appointments Commission information
- Individual dialogue and contributions from NHS Workforce, Equality & Human Rights Group, Appointments Commission and NHS Employers

7.7 A diverse workforce – the Department of Health

Supported by:

- Review of Public Service Agreements
- Review of *Promoting Equality, Valuing Diversity: A strategy for the civil service*[38]
- Desk/literature review of reports on civil service diversity
- Individual discussions and information exchange with Department of Health Human Resources Directorate
- Individual discussion EnABLE Chair and other staff with long term conditions

Consultation and focus groups

7.8 The involvement of disabled people and disability stakeholders in deliberative events and focus groups is included as part of the overall evidence for this report. Key workshops were those involving a broad range of disabled people and disability stakeholder organisations on 23 January and 29 October 2008.

7.9 As far as possible, direct output from the workshops was used to focus the report on what disabled people told us they are interested in. Further opportunities for involvement and continued engagement are expected as a result of this report and other key reports on disability to be published, the proposed deliberative event following this report publication (January 2009) and the equality stakeholder review which is outlined in Chapter 2.

Examples of good practice

7.10 Examples of good practice help illustrate the progress disabled people have made in health and social care, either as staff members or patients. The original commission to stakeholders asked particularly for information on the participation of disabled people in governance of programmes, as co-producers of assessments or partners in service delivery. The request was issued to Departmental policy officials with a clear stake in the disability equality agenda and strategic health authority equality leads for dissemination at local level. A snapshot of some examples is in Annex B to this report.

Report review and evaluation

7.11 An evaluation of the whole process will be undertaken to identify the baseline from which progress can be measured as part of the next report under this duty. The report process underwent equality screening which informed aspects of the analysis.

Overview of evidence available

7.12 The Information Centre (a special health authority that collects and reports on a wide variety of information to help the NHS and social services run effectively) was the main source of data. UNIFY, the Department of Health web-based database containing NHS Vital Sign indicator performance was used, supported by direct information from health inequalities and long-term conditions analysts.

Overview of data gaps identified

7.13 Information on the progress of disabled people is still not collected in one place, and at local level is split between primary care trusts and local authorities. This results in gaps and overlap and some inconsistencies. Whereas the information was used and area analysis undertaken, it presents a challenge in robustly tracking the progress of disabled people through the health and social care system.

7.14 We found differences with definitions of disaggregation by impairment that had been previously acknowledged by the Office of National Statistics and ODI. Some datasets were more detailed than others. Without standard definitions, we cannot exploit the richness of some of the data that is already available. Rapid agreement across public authorities on standard definitions would go some way to tracking progress in future reports.

Improving the evidence

> *'We are not suggesting the need for burdensome or expensive new systems of data collection, but rather the better use of existing data sources. The modification of existing data sources, by adding disability related questions, is a[sic] cost effective'*
>
> Disability Rights Commission, 'Up to the Mark', 2007

7.15 There have been some successes such as the data and analytical tools now publicly available through the Information Centre and the agreement to disaggregate and analyse the NHS Vital Sign indicators by equality strands. This was the result of joint working across the Department including Performance, Information Centre, Equality & Human Rights Group and others. This will add greater quality to the evidence available for Equality Impact Assessments, leading to improved policy making.

7.16 The information will be included in the new database of evidence being developed as part of the Equality Impact Assessment programme in the Department of Health and proposals for making that available to local NHS organisations will be considered.

7.17 The establishment of the Equality Monitoring Group under the Chairmanship of the Department of Health Permanent Secretary, has enabled high level focus to be directed on identifying opportunities and securing the opening up datasets, disaggregation of existing data and for collecting better quality and new data.

Wider government action to improve evidence

7.18 The ONS led Equalities Data Review highlighted areas where there are current equality data gaps and inconsistencies in the inequalities evidence base. The report made recommendations for the ONS and other government bodies to improve coordination and processes, data comparability and quality, and data accessibility and presentation.

7.19 The ONS highlighted where they would work in partnership with the Office for Disability Issues to play a leading role for delivering in three specific areas:

- developing, agreeing and championing a consistent approach to collecting information on disability widely across Government and the wider public sector;
- developing best practice methods and publishing guidelines for research with those who are frequently excluded from mainstream data collection methods, for example those with learning difficulties or those requiring proxy interviews; and
- developing good practice guidance for improving the physical accessibility of data and information for a diverse user group.

7.20 The Office for Disability Issues has commissioned the ONS to develop a longitudinal disability survey of Great Britain. The survey will explore the barriers disabled people experience from the social model perspective and become a major new source of statistical information on disability issues. It will provide data on the key topics disabled people have told us are a priority as we measure progress towards equality by 2025. The survey development involves a cross-government steering group of other departments and a reference network of disabled people and their organisations to inform each stage of survey development work.

7.21 An Equality Measurement Framework (EMF) is also being developed by the Equality and Human Rights Commission. Together with the Government Equalities Office and others, this will evaluate progress towards achieving equality in Britain, with particular attention to gender (including transgender), ethnicity, disability, sexual orientation, age, religion or belief, and social class, and incorporate the perspective of human rights.

Underpinning indicators

7.22 Throughout this report we have considered national and local measures as set out by the Public Service Delivery Agreements and how these are translated into NHS Operating Framework Vital Sign indicators and Local Area Agreement National Indicators. These are tabled below with the table showing the National Indicator Set indicator, the corresponding Vital Sign indicator, the related Public Service Agreement ort Departmental Strategic Objective equivalent and the total number of Local Area Agreements containing plans for that indicator.

LAA NI	Vital Sign	PSA/ DSO	Indicator	Coverage in LAAs (total no.)
51	VSB12	PSA12	Effectiveness of Children and Adolescent Mental Health Service (CAMHS) (percentage of PCTs and LAs who are providing a comprehensive CAMHS)	53
54	VSC33	PSA12	Parents experience of services for disabled children	31
119	VSC31	DH DSO	Self-reported measure of people's overall health	14
120	VSB01	PSA18	All-age all cause mortality rate per 100,000 population	56
124	VSC11	PSA19	Proportion of people with long-term conditions supported to live independently and in control of their condition	29
125	VSC04	PSA18	Proportion of people achieving independence 3 months after entering intermediate care/rehabilitation – rate per 10,000	48
127	VSB15	PSA19	Self-reported experience of social care users	5
128	VSC32	DH DSO	Patient and user-reported measure of respect and dignity in their treatment	11
129	VSC15	DH DSO	End of life care – access to appropriate care enabling people to be able to choose to die at home	9
130	VSC18	DH DSO	Adults and older people receiving direct payments and/or individual budgets per 100,000 population (18 and over)	92
131	VSC10	DH DSO	Number of delayed transfers of care per 100,000 population (aged 18 and over)	15
132	VSC12	DH DSO	Timeliness of social care assessment	14
133	VSC13	DH DSO	Timeliness of social care packages	6
134	VSC20	DH DSO	Number of emergency bed days per head of weighted population	17
135	VSC18	DH DSO	Proportion of carers receiving needs assessment or review and a specific carer's service, or advice and information as a percentage of clients receiving community based services	91
136	VSC03	PSA18	Proportion of adults (18 and over) supported directly through social care to live independently at home	52
140	N/A	PSA15	Fair treatment by local services	16
141	N/A	CLG DSO	Percentage of vulnerable people achieving independent living	76
142	N/A	PSA17	Percentage of vulnerable people who are supported to maintain independent living	48
146	VSC07	PSA16	Proportion of adults with learning disabilities in employment	37
145	VSC05	PSA16	Proportion of adults with learning disabilities in settled accommodation	13
149	VSC06	PSA16	Proportion of adults with secondary mental health services in settled accommodation	12
150	VSC08	PSA16	Proportion of adults in contact with a secondary mental health service in employment	40
151	N/A	PSA16	Overall employment rate	44

Qualitative evidence obtained through workshops with disability equality stakeholders

7.23 A workshop was held on 23 January 2008 with a total of 66 individual disabled and disability focused stakeholders. The key findings from this event are highlighted throughout this report and many of the issues addressed are being taken forward as part of the 2008 Department of Health Single Equality Scheme, as well as implementation of next steps arising from this report. Workshop discussions focused on

- Departmental priorities for disability equality;
- Involvement, consultation and evidence based commissioning;
- Building accessibility into policy and service design.

23 January 2008 workshop participants:

ACE Centre; Arthritis Care; Breakthrough UK Ltd; British Institute of Learning Disabilities; Deafblind UK; Diabetes UK; Dimensions; East Sussex Disability Association; Equal Access; Equality First; Eye to Eye Campaign; Guide Dogs; Hearing Dogs for Deaf People; Help First; KIDS, Yorkshire and the Humber; Limbless Association; Linkage Community Trust; Location Action Group; Mencap; National Autistic Society; National Federation of the Blind of the UK; Reece Disability Equality Training; Royal National Institute of Blind People; Royal National Institute for the Deaf; SeeAbility; SignHealth; United Response; Vitalise; Whizz-Kidz; Berkshire West PCT; Bristol PCT; Central Lancashire PCT; City and Hackney Teaching PCT; GLR Consulting; OPM; Royal College of General Practitioners; Royal College of Nursing.

7.24 A workshop was held on 29 October 2008 with a total of 50 individual disabled and disability focused stakeholders. The key findings from this event are highlighted throughout this report and many of the issues addressed are being taken forward.

7.25 We will publish an overview of the workshop, with agreement, as part of the follow up to this report. This will be published on the Department's website at http://www.dh.gov.uk/en/Managingyourorganisation/Equalityandhumanrights/index.htm.

Annex A: References

Publications referenced in this report

[1] *A Life like Any Other? Human Rights of Adults with Learning Disabilities.* (March 2008). The House of Lords and House of Commons Joint Committee on Human Rights. http://www.publications.parliament.uk/pa/jt200708/jtselect/jtrights/40/40i.pdf)

[2] *A Life Like No Other: A National Audit of Specialist Inpatient Healthcare Services for people with Learning Difficulties in England*. (December 2007). Healthcare Commission. http://www.healthcarecommission.org.uk

[3] *A Sure Start to Later Life- Ending Inequalities for Older* People: A Social Exclusion Unit Final Report. (January 2006). Office of the Deputy Prime Minister. http://www.communities.gov.uk/documents/corporate/pdf/913275.pdf

[4] *Aiming High for Disabled Children: Better support for families*. (May 2007). HM Treasury – Department for Education and Skills. http://www.dh.gov.uk/

[5] *Assisted Living Innovation Platform*. Technology Strategy Board. http://www.innovateuk.org/ourstrategy/innovationplatforms/assistedliving.ashx

[6] *Better Care, Better Lives: Improving Outcomes and Experiences for Children, Young People and their Families Living with Life-Limiting and Life- Threatening Conditions.* (February 2008). Department of Health. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_083106

[7] *Books Beyond Words*. The Royal College of Psychiatrists http://www.rcpsych.ac.uk/publications/booksbeyondwords.aspx

[8] *Capturing the Value of the Disability Equality Duty: Early Impact, Benefits, and Lessons Learnt Across Five Central Government Departments.* (May 2007). Disability Rights Commission. http://www.drc.org.uk/pdf/Capturingfinal%20report.pdf

[9] *Choosing Health: Supporting the Physical Health Needs of People with Severe Mental Illness*. (August 2006). Department of Health. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4138212

[10] Convention on the Rights of Persons with Disabilities http://www.un.org/disabilities/default.asp?id=259

[11] *Commissioning Framework for Health and Wellbeing*. (March 2007). Department of Health. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyandGuidance/DH_072604

[12] *Count me in 2007: Results of the 2007 national census of inpatients in mental health and learning disability services in England and Wales*. (November 2007). Healthcare Commission http://www.healthcarecommission.org.uk/_db/_documents/Count_me_in-2007.pdf

[13] *Creating a Disability Equality Scheme: A Practical Guide for the NHS*. (October 2006). Department of Health. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4139666

[14] *Cutting the cake fairly: CSCI review of eligibility criteria for social care.* (October 2008). Commission for Social Care and Inspection. http://www.csci.org.uk/about_us/publications/cutting_the_cake_fairly.aspx

[15] *Death by Indifference* (March 2007). Mencap. http://www.mencap.org.uk/case.asp?id=52&menuId=53&pageno

[16] *Delivering a Diverse Civil Service: A 10-Point Plan.* (November 2005). Civil Service Communications. http://www.civilservice.gov.uk/iam/diversity/10point/index.asp

[17] *Doing Time: The Experiences and Needs of Older People in Prison.* (2008). Prison Reform Trust. http://www.prisonreformtrust.org.uk/temp/DoingspTime.pdf

[18] *Equal to the task: How Overview and Scrutiny Can Help Local Authorities Meet their Equalities Duties.* (September 07). The Centre for Public Scrutiny. http://www.dotheduty.org/files/Equaltothetask.pdf

[19] '*Equal Treatment – Closing the Gap*': *A formal investigation into physical health inequalities experienced by people with learning disabilities and/or mental health problems.* (July 2006). Disability Rights Commission. http://www.equalityhumanrights.com/en/publicationsandresources/Pages/DRCHealthFImainreportpart1.aspx

[20] *Equality and Diversity in LAAs: A Aide Memoir for Locality Managers*. Government Equalities Office. http://equalities.gov.uk/

[21] *Framework for a Fairer Future – The Equality Bill*. (June 2008). Government Equalities Office. http://www.equalities.gov.uk/publications/FRAMEWORK%20FAIRER%20FUTURE.pdf

[22] *Healthcare for All: Independent Inquiry into Access to Healthcare for all People with Learning Disabilities.* (July 2008). Sir Jonathan Michael. http://www.iahpld.org.uk

[23] *High Quality for All: NHS Next Stage Review Final Report.* (June 2008). Department of Health. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_085825

[24] *Improving Access to Psychological Therapies*. (April 2007). Department of Health. http://www.dh.gov.uk

[25] *Improving Health and Care: Changing Lives – The government's response to Dame Carol Black's Review*. (November 2008). Department for Work and Pension and Department of Health. http://www.info4local.gov.uk/documents/publications/1072951

[26] *Independent Living Strategy- A Cross-Government Strategy about Independent Living for Disabled People*. (March 2008). Office for Disability Issues. http://www.officefordisability.gov.uk/docs/ilr-executive-report.pdf

[27] *Independence, Well-being and Choice: Our Vision for the Future of Social Care for Adults in England*. (March 2005). Department of Health. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4106477

[28] *Involvement for Real Equality: the benefits for public services of involving disabled people*. (September 2007). Report for the Disability Rights Commission written by the Office for Public Management. http://www.equalityhumanrights.com

[29] *LAC (Local Authority Circular) (DH) (2008)1: Transforming social care*. (January 2008). Department of Health. http://www.dh.gov.uk/en/Publicationsandstatistics/Lettersandcirculars/LocalAuthorityCirculars/DH_081934

[30] *National Dementia Strategy*. (2008). Department of Health. http://www.dh.gov.uk/en/socialcare/deliveringadultsocialcare/olderpeople/nationaldementiastrategy/index.htm

[31] *NHS Next Stage Review: Leading Local Change*. (May 2008). Department of Health. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_084644

[32] *Our Health, Our Care, Our Say: a New Direction for Community Services*. (January 2006). Department of Health. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyandGuidance/DH_4127453

[33] *Our NHS, Our Future Next Stage Review*. (July 2008). Department of Health. http://www.dh.gov.uk/en/Healthcare/OurNHSourfuture/index.htm

[34] *Overview of Primary Care Trust Disability Equality Scheme assessments by the Disability rights Commission*. (September 2007). Disability Rights Commission. www.dotheduty.org/files/PCTs_and_the_DED.rtf

[35] *Pacesetter Programme*. Department of Health http://www.dh.gov.uk/en/Managingyourorganisation/Equalityandhumanrights/Pacesettersprogramme/index.htm

[36] *Pathways to Work*. (April 2008). Department of Work and Pensions. http://www.dwp.gov.uk/welfarereform/pathways.asp

[37] *Promoting equality – Response from Department of Health to the Disability Rights Commission Report, Equal Treatment: Closing the Gap*. (March 2007). Department of Health. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_072955

[38] *Promoting Equality, Valuing Diversity – A Strategy for the Civil Service*. (July 2008). Civil Service. http://www.civilservice.gov.uk/about/diversity/summary.asp

[39] *Putting People First: A Shared Vision and commitment to the transformation of social care*. (December 2007). Department of Health http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndguidance/DH_081118

[40] *Real Involvement: Working with People to Improve Health Services.* (October 2008). Department of Health. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_089787

[41] *Review of Children and Young People.* (Jan 2007). HM Treasury and Department of Education and Skills. http://www.hm-treasury.gov.uk/d/cyp_policyreview_ypversion.pdf

[42] *Securing Better Mental Health for Older Adults.* (July 2005). Department of Health. http://www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/Olderpeople/Browsable/DH_4113714

[43] Single Equality Scheme. (December 2006). Department of Health http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_063287

[44] *10 Steps to your SES: A Guide to Developing a Single Equality Scheme.* (February 2007). Department of Health. http://www.dh.gov.uk/en/Managingyourorganisation/Equalityandhumanrights/browsable/DH_066006

[45] *The Bercow Report- The Review of Services for Children and Young People (0-19) with Speech, Language and Communication Needs.* (July 2008). Department for Children, Schools and Families. http://www.dcsf.gov.uk/bercowreview/

[46] *The Local Government and Public Involvement in Health Act 2007.* (December 2006). The Department of Health. http://www.opsi.gov.uk/acts/acts2007/ukpga_20070028_en_1

[47] *The NHS in England: The operating framework for 2008/9*. (December 2007). Department of Health http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_081094

[48] *The Public Sector and Equality for Disabled People: Research Report 343.* (2006). Department of Work and Pensions. http://www.dwp.gov.uk/asd/asd5/rports2005-2006/rrep343.pdf

[49] *The Strategic Health Authorities and the Disability Equality Duty.* (2008). Civil Service Communications. http://www.civilservice.gov.uk

[50] *Time to Change- Lets End Mental Health Discrimination* Campaign http://www.time-to-change.org.uk/

[51] *Together for Disabled Children.* http://www.togetherfdc.org/default.aspx

[52] *Treat Me Right: Better Healthcare for People with Learning Disability.* (July 2004). Mencap. http://www.mencap.org.uk/document.asp?id=316

[53] *Up to the Mark? How have Government Departments responded to the new Disability Equality Duty?* (June 2007). Disability Rights Commission. http://83.137.212.42/sitearchive/drc/employers_and_service_provider/disability_equality_duty/putting_the_duty_into_practice.html

[54] *Valuing People's Oral Health: A good practice guide for improving the oral health of disabled children and adults.* (November 2007). Department of Health. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_080918

[55] *Valuing people now: from progress to transformation – a consultation on the next three years of learning disability policy.* (March 2008). Department of Health.
http://www.dh.gov.uk/en/Consultations/LiveConsultations/DH_081014

[56] *Work Capability Assessment*. (October, 2008). Department of Work and Pensions.
http://www.dwp.gov.uk/esa/healthcare-professionals-esa.asp

[57] *Working for a Healthier Tomorrow: Dame Carol Black's Review of the Health of Britain's Working Age Population.*(March 2008). Health Work Wellbeing.
http://www.workingforhealth.gov.uk/documents/working-for-a-healthier-tomorrow-tagged.pdf

[58] *World Class Commissioning*. (2008). Department of Health.
http://www.dh.gov.uk/en/Managingyourorganisation/Commissioning/Worldclasscommissioning/DH_083197

[59] *You can make a difference: improving primary care services for disabled people – discussion note for Primary Care Trusts.* (September 2004). Department of Health and Disability Rights Commission.
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/Browsable/DH_4094426

Other useful publications

Are we Choosing Health? The Impact on Policy on the Delivery of Health Improvement Programmes and Services. (July 2008). Healthcare Commission and Audit Commission.
http://www.healthcarecommission.org.uk/_db/_documents/Are_we_choosing_health_tagGed.pdf

Capturing the Value of the Disability Equality Duty: Early impact, benefits and lessons learnt across five central government departments. (May 2007). Report for the Disability Rights Commission
http://www.drc.org.uk/pdf/Capturingfinal%20report.pdf

Children's Mapping Service
http://www.childrensmapping.org.uk/

Commissioning Specialist Adult Learning Disability Services – Good Practice Guide. (October 2007). Department of Health
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_079987

Disability Equality: How will we know we are making a difference?
Summary of the results of consultation. (November 2007). Office for Disability Issues
http://www.officefordisability.gov.uk/docs/consultations/ded-difference.pdf

Evaluation of the Individual Budget Pilot Projects (October 2008). Department of Health
http://www.dh.gov.uk/en/SocialCare/Socialcarereform/Personalisation/index.htm

Disability Equality Duty Secretary of State Reports: Getting Started. (August 2007). Office for Disability Issues
http://www.officefordisability.gov.uk/docs/guidancefordepartments.pdf

Improving the life chances of disabled people. (January 2005). Cabinet Office.
http://www.cabinetoffice.gov.uk/strategy/work_areas/disability/~/media/assets/www.cabinetoffice.gov.uk/strategy/disability%20pdf.ashx

The Local Basket of Indicators. (2008). London Health Observatory.
http://www.lho.org.uk/HEALTH_INEQUALITIES/Basket_Of_Indicators/BasketOfIndicatorsDataTool.aspx

National Indicators for Local Authorities and Local Authority Partnerships: Handbook of Definitions First release (February 2008). Communities and Local Government.
www.communities.gov.uk/documents/localgovernment/pdf/708685

Not just sticks and stones: a survey of the stigma, taboos and discrimination experienced by people with mental health problems. (November 1996), Read J. and Baker S, MIND.
http://www.leeds.ac.uk/disability-studies/archiveuk/Baker/MIND.pdf

Office of the Third Sector. Cabinet Office
http://www.cabinetoffice.gov.uk/third_sector/Research_and_statistics/third_sector_research.aspx

Participation Works
http://www.participationworks.org.uk/

Patient and Public Involvement Specialist Library http://www.library.nhs.uk/ppi/

People and Participation
http://www.peopleandparticipation.net/display/Involve/Home

Promoting Equality, Valuing Diversity – A Strategy for the Civil Service. (July 2008). Civil Service Communications.
http://www.civilservice.gov.uk/about/diversity/index.asp

Public Bodies' Response to the Disability Equality Duty: An Audit of Compliance with the Requirement to Publish a Disability Equality Scheme. (March 2007). Ipsos MORI on behalf on Office for Disability Issues.
http://www.officefordisability.gov.uk/publications/

The Duty to Promote Disability Equality: Statutory Code of Practice- Chapter 4.
Disability Rights Commission.
http://www.equalityhumanrights.com/Documents/DRC/Useful%20Documents/DED%20Code%20of%20Practice_England%20and%20Wales.rtf

The Experience of Visually Impaired Users of the NHS: A Survey. (2004)
Nzegwu F, The Guide Dogs for the Blind Association.
http://www.guidedogs.org.uk/index.php?id=2107

The Public Sector and Equality for Disabled People. (2006).
DWP Research Report No 343. BY CRSP and BMRB on behalf on DWP
http://www.dwp.gov.uk/asd/asd5/rrs2006.asp#pubsector

Annex B: Resources

Summary examples of disabled people involvement

Policy/ Programme	Consultation Involvement of people with Disability	Policy Planning and Evaluation- Involvement of People with disability	Programme Governance Involvement of people with disability on programme boards	Policy Accessibility Access (incl easy read and Braille documents)
Transforming Adult Social Care (TASC) 'Putting People First'	Working with key stakeholders who are also users of services to set up Transforming Adult Social reference group (under development)	The evaluation specifically looks at the impact on users. The draft EQIA for personalisation workstream of programme based on evidence from DPs	Proposing to recruit 20 users to a reference group, which will represent a broad range of user interests.	Part of the user engagement work will involve looking at accessibility for the user group and wider public access
Transforming Community Equipment Programme	The programme was commissioned to develop a retail model for the provision of community equipment and wheelchairs. From the outset users and carers, including parents and disabled children have been involved and engaged. The programme team worked with 226 stakeholders, from a broad range of backgrounds; they also worked with 11 councils and health partners to understand their current service.	The open process used to engage users, carers and other stakeholders in this programme meant that participates were self-selecting. A poll of customer satisfaction was commissioned to ensure qualitative information was available and the results were overwhelmingly positive	Programme was guided by a sector-wide steering group including users and user led organisation representatives. Lead sites also worked with their local populations to develop their local retail models.	
Mental Health Act (MH Act)	For the Mental Health Act a workshop was held with learning difficulties service users as part of consultation for secondary legislation and code of practice.	Service users are involved in all areas of planning and development of policies within the Mental Health Programmes.	Mental Health Services user members on Management Board	Easy read guides to code of practice and secondary legislation

Policy/ Programme	Consultation Involvement of people with Disability	Policy Planning and Evaluation- Involvement of People with disability	Programme Governance Involvement of people with disability on programme boards	Policy Accessibility Access (incl easy read and Braille documents)
Improving Access to Psychological Therapies Programme (IAPT)	For Improving Access to Psychological Therapies Programme a bi-monthly meeting is held with pathfinder and demonstration site user groups. New Horizons, is a regional focus group, of a mental health service users to set a vision for Mental Health Services post end of NSF in 2009	Service users are involved in all areas of planning and development of policies within the Mental Health Programmes. EQIA signed off in July	Mental Health Services user member of Programme Board	Easy read leaflet produced providing information on IAPT programme
Delivering Race Equality (DRE)	All Delivering Race Equality work has involved extensive consultation with service users and BME communities. Consultation is continuing through these national groups and other representative organisations.		There is a national service user group as well as some regional service user groups.	
Improving Life Chances	Improving the Life Chances of Disabled People report recommended that by 2010 each local authority area should have a user-led organisation. These are led and controlled by disabled people.	EQIAs were carried out on the User-Led organisations project	Disabled people were involved in the design of the events around User-Led Organisations and in their facilitation	Information on User Led Organisations is available in easy read
Valuing People Now	Valuing People Now consultation was published in December 2007. This consultation was open to everyone to respond. 2000 responses were received, with 39% from people with learning disabilities.	A full impact assessment and equality impact assessment was completed in October 2008 for Valuing People Now involving disabled people	Some people with disabilities are members of the Learning Disability Programme Board which meets up quarterly	An easy-read document of the Valuing People Now consultation was available. An easy-read document of the final publication will be available

Policy/ Programme	Consultation Involvement of people with Disability	Policy Planning and Evaluation-Involvement of People with disability	Programme Governance Involvement of people with disability on programme boards	Policy Accessibility Access (incl easy read and Braille documents)
Promoting Equality (DH 2006) DRC Working Group	The Promoting Equality action plan was written in response to DRC's report Closing the Gap. The DRC consulted widely with people with learning disabilities by means of questionnaire for both the Closing the Gap and Valuing People Now report. Presentations and workshop style consultations have also been given on the Promoting Equality workstream at two national conference targeting people with learning disabilities, family carers and specialist health staff and also to the Learning Disability task force.	Impact Assessment and Equality assessment undertaken as part of Valuing People Now (2008) redraft	The National Director for people with learning disabilities is a member of the Learn Disability Task force and reports to the DRC working group. Valuing People advisor host local networks of self advocacy groups, which feed into the Valuing People Programme Board. The Chair of the Promoting Equality Group reports to this group.	The questionnaires used easy read and both of the presentations were made accessible to people with learning disabilities using photograph and easy words. An easy read consultation document of 'Valuing People Now' has been distributed. All external correspondence regarding events is in easy read language
South West Strategic Health Authority Equality and Human Rights	Disabled people were invited to attend three meetings located around UK to discuss the Strategic Health Authority's disability equality scheme and action plan (28 people attended). A disability equality reference group is being established	The disability equality reference group will be used to assist with undertaking of EQIA.		The Single Equality Scheme for 2009-2012 which is being consulted on is being produced in an easy read format.
National Social Inclusion Programme (NSIP)	Programme has had service user and carer involvement right from the start.	A reference group was established which consists of 15 service users and carers who are paid for their involvement work and cover a wide geographical area and interests.	Reference group set up to capitalise on expertise and experience within the group.	

Policy/ Programme	Consultation Involvement of people with Disability	Policy Planning and Evaluation- Involvement of People with disability	Programme Governance Involvement of people with disability on programme boards	Policy Accessibility Access (incl easy read and Braille documents)
Partnerships for Older People Projects (POPP)	An advisory group was established. This group is chaired by an older person and the membership is made up of older people from across the country, who represent a range of interests. Two workshops were held in collaboration with BGOP and Help the Aged to seek the views of older people on the issues that mattered to them and also on specific ideas contained within the POPP proposals			

DH Department of Health

291124 1p Dec 08
Produced by COI for the Department of Health

www.dh.gov.uk/publications