

Prime Minister's Strategy Unit

Improving the life chances of disabled people

Final Report

January 2005

A joint report with:

Department for Work and Pensions

Department of Health

Department for Education and Skills

Office of the Deputy Prime Minister



This report is joint with the following departments:



Office of the
Deputy Prime Minister

Creating sustainable communities

DWP

Department for
Work and Pensions



Department
of Health

department for

education and skills

creating opportunity, releasing potential, achieving excellence

Contents

	Page No
Foreword by the Prime Minister	5
Executive summary	7
1. Introduction	21
2. The current situation and its causes	33
3. Vision and strategy	53
4. Independent living	69
5. Early years and family support	101
6. Transition to adulthood	125
7. Employment	155
8. Towards improved delivery	195
9. Implementation	217
Annex A The role of the Strategy Unit	235
Annex B Project team, Sponsor Minister, Advisory Group and Expert Groups	237
Annex C Bilateral discussions and an overview of the consultation processes	241
<p>The following annexes can be found on the Strategy Unit website (www.strategy.gov.uk):</p>	
Annex D A review of focus group consultations	
Annex E A review of the main messages from responses to the analytical report	
Annex F The results of a literature review of the specific issues faced by disabled people with the most complex needs	

Foreword by the Prime Minister



Getting a job or education, travelling between home and work, going for a drink or to the cinema with friends are activities most of us take for granted. But for too many disabled people these ordinary aspects of life remain difficult to achieve.

That is why I asked the Strategy Unit to look at what more we can do to improve disabled people's opportunities, to improve their quality of life and strengthen our society. Despite considerable progress, disabled people are still experiencing disadvantage and discrimination. Barriers – in attitudes, the design of buildings and policies, for example – still have to be overcome by disabled people, reducing their opportunities and preventing them fulfilling their potential. Too many services are

organised to suit providers rather than being personalised around the needs of disabled people.

Nor is this a marginal issue. Up to one in five British adults is disabled and can find themselves cut off from the opportunities others enjoy. And our economy and society, too, lose out if we don't use their talents to the full.

This Government is committed to improving the life chances of disabled people. Through the Disability Discrimination Act and the creation of the Disability Rights Commission, new rights are being provided and enforced. We are helping disabled people to get back into work through the New Deal and to have personalised support through Direct Payments.

But despite progress, there is more to do. Disabled people remain more likely to live in poverty, to have fewer educational qualifications, to be out of work and experience prejudice and abuse. They still routinely find themselves experiencing poorer services.

This report therefore sets out an ambitious vision for improving the life chances of disabled people so that by 2025 disabled people have full opportunities and choices to improve their quality of life and will be respected and included as equal members of society.

I strongly welcome this report and its recommendations, which will be taken forward and implemented as future Government policy. All sections of society will of course have a role to play in realising our vision. But working together I believe we can achieve the transformation in disabled people's life chances that we all seek.

A handwritten signature in blue ink that reads "Tony Blair". The signature is written in a cursive style and is underlined with a single horizontal line.

Tony Blair

1 Executive Summary

Key Points

This report sets out an ambitious programme of action that will bring disabled people fully within the scope of the “opportunity society”. By supporting disabled people to help themselves, a step change can be achieved in the participation and inclusion of disabled people.

The report proposes that the Government should set an ambitious vision for improving the life chances of disabled people. **‘By 2025, disabled people in Britain should have full opportunities and choices to improve their quality of life and will be respected and included as equal members of society’.**

Future strategy for disabled people should seek to realise this vision through practical measures in four key areas.

- (1) Helping disabled people to achieve **independent living** by moving progressively to individual budgets for disabled people, drawing together the services to which they are entitled and giving them greater choice over the mix of support they receive in the form of cash and/or direct provision of services. In the shorter term, measures should also be taken to improve the advice services available to disabled people and to address existing problems with suitable housing and transport.
- (2) Improving support for **families with young disabled children** by ensuring families of disabled children benefit from childcare and early education provided to all children; meeting the extra needs of families with disabled children; and ensuring services are centred on disabled children and their families, not on processes and funding streams.
- (3) Facilitating a smooth **transition into adulthood** by putting in place improved mechanisms for effective planning for the transition to adulthood and the support that goes with this; removing “cliff edges” in service provision; and giving disabled young people access to a more transparent and more appropriate menu of opportunities and choices.

(4) Improving **support and incentives for getting and staying in employment** by ensuring that support is available well before a benefit claim is made; reforming the gateway onto entitlements; providing effective work-focused training for disabled people; and improving Access to Work and other in-work support – all of which will see more disabled people in work, contributing to the Government's overall targets for employment.

This package of measures extends choice and improves incentives for disabled people. It should deliver improved outcomes for disabled people, their families and wider society in the short, medium and long-term. The Government has accepted all the recommendations in this report. The strategy will now be driven forward by a new Office for Disability Issues reporting to the Minister for Disabled People. Annual reports on progress will be presented to the Prime Minister and published on the web. Implementation of these measures should take account of the needs of older people who are disabled or who have care requirements.

Disability should be distinguished from impairment and ill health

For the purposes of this report, disability is defined as:

- **disadvantage** experienced by an individual ...
- ... resulting from **barriers** to independent living or educational, employment or other opportunities ...
- ... that impact on people with **impairments** and/or ill health.

A clear distinction needs to be made between disability, impairment and ill-health. Impairments are long-term characteristics of an individual that affect their functioning and/or appearance. Ill health is the short-term or long-term consequence of disease or sickness.

Many people who have an impairment or ill health would not consider themselves to be disabled.

Disabled people face a wide range of barriers

The types of barriers faced by disabled people include:

- **attitudinal**, for example among disabled people themselves and among employers, health professionals and service providers;
- **policy**, resulting from policy design and delivery which do not take disabled people into account;
- **physical**, for example through the design of the built environment, transport systems, etc.; and
- those linked to **empowerment**, as a result of which disabled people are not listened to, consulted or involved.

The cumulative effect of these barriers is to marginalise disabled people from the mainstream of society and the economy. Removal of these barriers is key to empowering disabled people, and giving them the opportunity to exercise their responsibilities as citizens – in the home, in the community and in the workplace. It is time to end the culture of dependency and low expectations, and move towards a society in which we invest in disabled people, empowering and supporting them to participate and be included.

The population of disabled people is large ...

Using the widest survey definition, it is estimated that there are about 11 million disabled adults in the UK – one in five of the total adult population – and 770,000 disabled children. Many of these people would not define themselves as disabled. The majority of these people experience low level impairments – wheelchair users, blind people and Deaf people make up an important minority. The population of disabled people is distinct from and much larger than the three million people in receipt of disability related benefits.

... highly diverse ...

The population of disabled people is highly diverse. It includes people from all age groups and across the income and education spectrum.

There are large differences in impairment experienced by disabled people. Because of this, generalisations are often unhelpful. Disabled people with different impairments, from different socio-demographic backgrounds and facing different barriers will have very different day-to-day experiences.

... and changing

Older people are more likely to be disabled than younger people, but over the past thirty years the incidence of disability has risen fastest amongst children – though it is not clear to what extent this simply reflects increased reporting. Trends in impairment show an increasing number of children being reported as having complex needs, Autistic Spectrum Disorders and mental health issues. Among adults there are increasing numbers of people reporting mental illness and behavioural disorders, while the number of people reporting physical impairments is decreasing. This report is primarily about the needs of disabled people below pension age, but many of the proposals in the report will help to improve the life chances of disabled people across the entire life-course.

Disabled people experience disadvantage in many aspects of daily life

Compared with non-disabled people, disabled people are:

- more likely to live in **poverty** – the income of disabled people is, on average, less than half of that earned by non disabled people;
- less likely to have **educational qualifications** – disabled people are more likely to have no educational qualifications;
- more likely to be **economically inactive** – only one in two disabled people of working age are currently in employment, compared with four out of five non-disabled people;
- more likely to experience problems with **hate crime or harassment** – a quarter of all disabled people say that they have experienced hate crime or harassment, and this number rises to 47% of people with mental health conditions;
- more likely to experience problems with **housing** – nine out of ten families with disabled children have problems with their housing;
- more likely to experience problems with **transport** – the issue given most often by disabled people as their biggest challenge.

However, the cause of this appears to work in both directions: people

are also more likely to become disabled if they have a low income, are out of work or have low educational qualifications.

The extent of the disadvantage is especially acute for some specific groups of disabled people

Disabled people often experience multiple forms of labour market disadvantage¹:

- More than 40% of disabled people are low-skilled
- Around 25% of disabled people of working age are over-50yrs
- Around 10% are from black and ethnic minority ethnic groups

For these groups there can be cumulative problems which add up to an even bigger impact on their life chances and quality of life.

Disabled people with some specific impairments face particularly poor outcomes. People with mental health conditions or learning disabilities have poorer educational qualifications, do much less well in the labour market and generally have lower incomes than other disabled people.

Disadvantage among disabled people has significant economic and social costs

The adverse outcomes experienced by many disabled people reduce quality of life both for disabled people themselves and for their families. Many disabled people

¹Data in this paragraph are from the Labour Force Survey (2001/02).

feel isolated, unwanted and a burden to society. Their families – parents, children and siblings – can also face negative attitudes, poverty and social exclusion. Many feel that they spend far too much time fighting bureaucracy – when they should be receiving the support they need to help themselves.

This has economic and social costs. Many disabled people are unable to make an effective contribution to their local community and economy – yet with the right support, they could be working and actively taking part. Disabled people currently out of work represent a significant pool of potential skills and abilities – if only that potential could be tapped, and expectations raised. Instead of being empowered to work, earn, spend and pay taxes, too many disabled people are left to depend on benefits and government support. And, poor economic outcomes during their working lives prevent disabled people from providing comfortably for old age, thus prolonging disadvantage into retirement.

Government intervention is justified on a number of grounds

Government intervention to improve the life chances of disabled people is a key element of building a genuine “opportunity society”. **Social justice** requires government to take steps to extend opportunities, choice and empowerment for disabled people, promote diversity and improve standards of living for all.

Such intervention will, in many cases, also bring net **benefits to the economy** – for example, through a widening of the skills base and an increase in productivity.

And in some cases, intervention will be justified on straight **value for money** grounds – for example, if more disabled people are helped into work, there will be increased tax revenues and lower spending on incapacity benefits.

Tackling these barriers is not a matter for government alone

Disabled people themselves, employers, health professionals, educators, local communities, and providers of goods and services all have a key role in improving the life chances of disabled people.

Disabled people’s experience of government support and services needs to change. Too often disabled people feel that they are fighting a system which is fragmented, complex and bureaucratic, and which does not put the needs of disabled people at the heart of service provision. Public service reform and investment has not yet benefited disabled people to the extent it should.

This report sets out an ambitious vision for improving the life chances of disabled people

A step change is needed in the way the disadvantage faced by disabled people is tackled. This cannot happen overnight – which is why

this report has established an ambitious 20-year vision:

“By 2025, disabled people in Britain should have full opportunities and choices to improve their quality of life, and will be respected and included as equal members of society.”

A radical strategy is needed to realise this vision – building on the progress made since 1997

This report sets out a long-term strategy for change. The strategy will empower and involve disabled people, personalise the support they receive and remove the barriers to inclusion and participation. It will build on the considerable progress that has already been made in promoting and protecting disabled people's rights, in improving choice and in supporting disabled people in education, employment and other forms of participation.

The centrepiece of the strategy must be the promotion of independent living

Independent living sits at the heart of this strategy. Independent living is not just about being able to live in your own home – though that is often part of it for many disabled people. Rather, independent living is all about providing disabled people with:

- choice;
- empowerment; and
- freedom.

This does not mean that disabled people are expected to do everything for themselves – but they are expected to have the biggest say in what they do and how they live their lives, and to take responsibility for their lives. The independent living agenda cuts across a number of different policy areas – social care, health care, housing, transport, education and beyond.

This report sets out first steps towards achieving the vision

Practical measures identified in this report fall under four main headings:

- independent living;
- support for families of young disabled children;
- transition into adulthood; and
- support and incentives for getting and staying in employment.

(1) Independent living

A way of supporting independent living should be put in place

A new way of supporting disabled people is needed, focused on the goal of independent living. Over time, this new approach should bring together existing funding streams that are currently fragmented, and which require disabled people to go through multiple assessments in order to access different forms of support.

The new approach should also allocate available resources from within the overall budget, according

to individual needs. Allocations should be in the form of individualised budgets that are made transparent to the disabled person. Disabled people – and the families of disabled children – should be able to choose whether they take their individualised budget in cash, in some combination of services and cash payments, or entirely as services commissioned by their local authority. The budgets should be used to get whatever type of support the individual needs – whether it is equipment, personal assistance, housing adaptations, help with transport to work or something else entirely.

The overall aim of the new approach should be to make sure that resources are allocated and services delivered in ways that:

- personalise responses to need;
- enable people to have choice and to be empowered over responses to need; and
- support disabled people to help themselves.

An important first step towards this new approach will be to test out some of the options

The new approach will require some radical changes to the way in which budgets are organised and services are delivered across a wide range of policy areas, government departments and local service providers. These changes will take time to get right – this report envisages that, subject to evaluation

evidence and availability of resources, national roll-out of a new system could take place by 2012.

Some of the elements for the design of this system will need to be piloted – this report envisages a staged approach. In the short term, the focus should be on working with local authorities – and where appropriate with Local Strategic Partnerships taking forward Local Area Agreements – who are already taking steps to introduce elements of this system. The aim should be to build a coherent evidence base, without adding to local authority burdens. In parallel, the case should be considered for an invest-to-save fund to be bid for in Spending Review 2006. The aim of such a fund would be to provide up-front resources to facilitate further evidence-building and to introduce the changes required by the new system.

Disabled people should be at the heart of these initiatives

One of the key ingredients for developing this new approach should be the direct involvement of disabled people, primarily through local Centres for Independent Living. The capacity within these organisations should be increased to enable them to play an effective part in supporting disabled people to achieve independent living. Centres for Independent Living are potentially well-placed to provide advice and information, advocacy support and practical assistance in managing individualised budgets.

Steps should also be taken to improve the provision of advice, housing and transport options for disabled people

Some needs of disabled people are so acute that it would be inappropriate to wait until the long-term to implement changes. This report therefore recommends specific changes to secure:

- improvements to the availability of independent advocacy;
- easier access to advice and information – so that all disabled people and their families understand their entitlements and rights;
- consideration of the adoption of updated Lifetime Homes standards and improvements to the use of accessible properties and Disabled Facilities Grants – making sure that disabled people can access housing accommodation which is more able to meet their needs; and
- increased local authority accountability for making sure that all aspects of disabled people's transport needs are taken into account.

(2) Early years and family support

The early years are a critical period for disabled children – many of whom live in child poverty

Child development and future life chances are critically affected by the

support and services received by young disabled children and their families. Targeting support at these families will also play a major role in delivering the Government's target to abolish child poverty – children from lower income households are more likely to report long standing illness or disability and mental health issues, reflecting a two-way relationship between low income and disability.

Families of disabled children should have access to individualised budgets – providing choice and control across multiple transitions

Families with young disabled children have additional needs which should be met. They may need specialist equipment or require housing adaptations. These needs may be specific to the child – such as assistive technology – or be part of the wider implications of having a disabled child with significant needs – such as need for home-based support.

Just like disabled adults, families of disabled children should, in due course, be able to access individualised family budgets to meet the additional needs arising from the child's impairment. These would address the needs of the family as a whole arising from the child's impairment, and so give the family choice and control over the support and services they receive.

Families of disabled children must be included in the support provided to all families

Early years and family support is a dynamic policy area with many new initiatives aimed at strengthening development and support for very young children. It is crucial that disabled children, alongside their non-disabled peers, are able to benefit from these reforms.

In the future, all national evaluations of children's services – including Sure Start – should specifically assess the impacts on families with disabled children, and recommend specific actions to address barriers to their inclusion. In addition, guidance for evaluations of children's services carried out at a local or regional level should be developed to make sure they take account of the needs of the local disabled children's population.

Key services for disabled children and their families must be centred on their needs, not on processes and funding streams

The fragmentation, complexity and bureaucracy of service provision are particularly acute for families of disabled children. This can create artificial barriers and inefficient restrictions – such as provision of transport between a child's school and home, but not including leisure facilities.

Individualised budgets will in due course play a key role in overcoming these barriers. But there are a

number of key services for which disabled children and their families must have effective access as soon as possible:

Disabled children and their families should have timely access to the equipment they need, when and where they need it. This will require common assessment processes and funding across health, education and social services, and will mean that equipment must be updated and maintained without delay.

All families with a disabled child should receive childcare provision which is sustainable, high quality, flexible, affordable and accessible – in other words, implementation of the 10-year Strategy for Childcare should include disabled children and their families on equal terms with non-disabled children and their families.

And a key worker should be in place for all families with high needs, to provide them with information, improve communication and coordinate early intervention. Availability of key workers should be considered for inclusion in the assessment of local social care and education services.

(3) Transition to adulthood

Effective support needs to remain available for disabled young people

The benefits of early years intervention will be lost if the transition through childhood and into adulthood is not managed

effectively. There are three key ingredients needed for effective support for disabled young people at the transition to adulthood.

- Planning for transition focused on individual needs.
- Continuous service provision.
- Access to a more transparent and more appropriate menu of opportunities and choices.

Over time, individualised budgets should mean a seamless transition from childhood to adult services

Individualised budgets should, in due course, give young disabled people and their families increased choice and control.

- Individual budget plans should be formulated in childhood and carried into adulthood and reviewed in response to changes in need, not age.
- User-led advice, information and advocacy services should be provided in every local authority to support families to manage their budgets, if they choose to do so.

In the shorter term, child and adult services should overlap to remove the 'cliff edge' in provision experienced by many disabled young people

Many disabled teenagers, especially those with learning difficulties, could benefit from children's services well beyond the current age cut-offs for those services. To address this,

child services such as Children's Trusts and the Family Fund should move to include all disabled people up to the age of 25, and should support disabled young people who are living at home or moving into independent living. At the same time, adult services such as the Expert Patients Programme should be made increasingly available to disabled young people.

Improved transitions require greater family support, personalisation, continuity, and opportunity

Alongside these other measures, transitions to adulthood should be improved for young disabled people through:

- the availability of **information** including accessible local and national information on transition processes, services and opportunities;
- mapping, dissemination and – in due course – national take-up of the most effective **person-centred processes** already in place at a local level; and
- ensuring that advice and guidance given to young disabled people, including **Connexions**, meets the needs of young disabled people.

(4) Employment

Recent government policy has delivered some significant improvements – but more is needed to improve the labour market status of disabled people

The Government has introduced a number of changes since 1997, including the New Deal for Disabled People, extensions to the Disability Discrimination Act 1995, the national minimum wage and Pathways to Work. These changes have improved incentives and assistance for people to move off benefits and into work, and have placed additional requirements on employers to employ disabled people. However, more is needed to improve the labour market status of disabled people, and to raise expectations for what disabled people can achieve in work. This report supports the national implementation of Pathways to Work, subject to evaluation and subject to resources being made available.

Future government policy should be designed to ensure that in twenty years time any disabled person who wants a job and needs support to get and keep a job anywhere in the country should, wherever possible, be able to do so. Any employer wanting to employ a disabled person should be able to find the right person and the right support. Recommendations to promote independent living will play a key role – but additional measures will also be needed.

Effective early intervention should help disabled people to stay in touch with the labour market

Too often, employment-focused support is not accessed until disabled people have spent some time out of work and away from the

labour market – either because they have never worked, or because they have been in a period of long-term “sickness absence”. Interventions at this late stage can be inefficient. This report makes two sets of recommendations which should ensure that support is provided earlier on in the process:

- A strategy for **work-focused rehabilitation**, building on the framework for vocational rehabilitation, should engage employers and health professionals, identifying best practice and making sure that the most effective use is made of the resources available;
- Building on Pathways to Work, **assessments** for incapacity benefit entitlement should be moved closer to the start of the claim, and should be used as much to assess what support is needed to enable someone to return to work, as to assess their benefit entitlement.

Steps should be taken to improve the employability of disabled people

There are two key elements to improving the employability of disabled people:

- Disabled people need to have the **skills** that employers want – compulsory education needs to play a key role in making sure that this is the case, but there should also be a role for more effective training and access to “lifelong learning” for disabled people;

- Disabled people should be able to have ready access to the personal support they need in order to work – this would require further improvements to the already successful **Access to Work** programme. At the same time, all employers should be able to access the effective advice and financial support to make the necessary workplace adjustments.

Disabled people should be able to access ongoing support personalised to their specific circumstances

Building on the success of the “New Deal” schemes, government is moving increasingly towards a **menu-driven** approach. People should be able to access support from a range of choices, focusing their own package of support on their own personal needs.

This report endorses the same approach for disabled people, ensuring that support is provided according to people’s needs, and is focused on enabling disabled people to maximise their potential and fulfil their aspirations. **Case managers** should be made available to help disabled people make the right choices, building on the way in which Jobcentre Plus personal advisers have been used in Pathways to Work. Over time, this should contribute towards achievement of much higher employment rates for disabled people, as a contribution to the achievement of a higher employment rate for the population as a whole.

Employers have a key role to play – but need to be able to access the right advice and information

This project has taken advice from an employers’ working group convened by the National Employment Panel. On the basis of this advice, this report recommends that employers should lead a campaign on the business benefits of employing disabled people with input from DWP and DTI. This should be backed up by improved access to information targeted specifically at employers.

All government departments will be responsible for driving forward this strategy and the implementation of these practical measures

The Government has accepted all the recommendations in this report. It will be the collective responsibility of all government departments to ensure that the recommendations in the report are taken forward. The report also establishes an Office for Disability Issues – reporting to the Minister for Disabled People – to help coordinate disability policy across government.

Annual reports on progress will be presented to the Prime Minister

Ongoing commitment to the vision and strategy in this report will be secured through a requirement for an inter-departmental report on progress to be presented annually to the Prime Minister and then published on the web.

Implementation of this package of measures should:

- increase disabled people's ability to live independently – to enjoy the same choice, control and freedom as any other citizen – at home, at work, and as members of the community;
- enable young disabled children and their families to enjoy 'ordinary' lives, through access to childcare, early education and early family support to enable them to care for their child effectively and remain socially and economically included;
- support disabled young people and their families through the transition to adulthood. Transition will be better planned around the needs of the individuals and service delivery will be smooth across the transition; and
- increase the number of disabled people in employment while providing support and security for those unable to work.

Successful implementation of the proposals in this report will depend, where necessary, on the appropriate level of funding being made available as a result of successful outcomes from future spending reviews. But in overall terms, a more efficient approach which promotes increased economic participation should deliver a net economic benefit in the medium to long term.

Chapter 1: Introduction

Summary

The main objective of the Strategy Unit (SU) project was to identify ways of improving the life chances of disabled people.

The report focuses on disabled children and disabled people of working age. However, the vision and strategy have been designed to ensure consistency with the approach to people over working age.

This report presents the project's conclusions and recommendations. The UK Government has made a commitment to implement the project's recommendations in England and, where appropriate, across the UK.

The project was carried out by a multi-disciplinary team including team members with experience in economics, social policy, local government and with expertise in disability issues.

This introductory chapter sets out the context and the aims of the project (Section 1.1). It then describes the scope and limitations of this report (Section 1.2). Recent developments in legislation and policy are highlighted in Section 1.3. The next section (1.4) defines some of the key terms and concepts used in the report. Details of how the project was conducted and who participated are provided in Section 1.5. Sections 1.6 and 1.7 outline the main phases of the project and next steps. Finally, Section 1.8 sets out the way in which the report is structured.

1.1 Project context

The Strategy Unit was set up in 2002 and reports to the Prime Minister through the Chancellor of the Duchy of Lancaster and the Cabinet Secretary. Its core business is providing the Prime Minister and government departments with a capacity to analyse major policy issues and design strategic solutions. (See Annex A for more details.)

The overall aim of this project was to identify ways of improving the life chances of disabled people

The Government has recognised that disabled people do less well than non-disabled people across a wide range of indicators of quality of life. Disabled people interact with a

range of government services, and face barriers that cut across departmental responsibilities. In this context, the Strategy Unit was asked by the Prime Minister to carry out a project which would:

- assess the extent to which disabled people are experiencing adverse economic and social outcomes in the UK;
- identify why this is happening, and what are its implications; and
- assess what could be done to improve the situation, in particular by making better use of existing resources.

This report presents the project's conclusions and recommendations

The project was announced in December 2003, and published an Interim Analytical Report in June 2004. This report marks the end of the project, and presents the projects conclusions and recommendations. The report has been accepted by the UK Government and there is a commitment to implement the project's recommendations in England and, where appropriate, across the UK. Options for implementation will also be discussed with the devolved administrations. The report should be seen as the start of a process of policy reform that will improve the life chances of all disabled people

and contribute to closing the attainment gap compared with non-disabled people.

1.2 Scope and limitations of this report

It is important to clarify from the outset groups that will be within the direct remit of this report

Disability affects all age groups. Some impairments and illnesses are particularly associated with ageing, while some people carry lifetime disability into retirement. This report is primarily about the needs of disabled people below pension age, but it is important to remember that those needs do not stop – and for some people only start – after pension age. Many of the proposals in the report will help to improve the chances of disabled people across the entire life-course, but this project has not considered in detail their interaction with policies and requirements affecting elderly people. The implementation of the recommendations will need to achieve consistency and avoid differences in treatment that are based purely on age².

The Government's Special Educational Needs (SEN) Strategy – *Removing Barriers to Achievement* – set out the Government's approach for supporting the learning of children with SEN. The Strategy was launched in February 2004 and will need to be fully evaluated once

² A consultation document on improving access to services to older people was published by the Department for Work and Pensions and the Local Government Association in August 2004. The proposals, published in a document called Link-Age, aim to simplify access to services and help by linking up provision across and beyond government, initially between the Pension Service and local authorities.

it has had time to take effect. For this reason, this report has not developed detailed proposals for disabled children in primary and secondary education.

There are limitations to the data available about the disabled population

Data on the numbers of disabled people and their characteristics are taken from population surveys. There are a number of limitations to these data. The accuracy of population estimates based on survey data will depend whether the sample used is representative of the population. Furthermore most data on disability relies on self-reporting, and for certain impairments – particularly mental health conditions – under-reporting may occur. To increase the reliability of estimates, a large sample size is needed – but is often not available, particularly when data is disaggregated by impairment type. This means that it is not always possible to disaggregate the population and discuss specific characteristics such as average education levels or employment rates reliably. Such analysis has therefore been left out of this report.

In devolved areas of policy the recommendations will apply to England only

The devolved administrations of Scotland and Wales have responsibility for devolved issues; therefore the conclusions in these areas apply to England only.

The devolved administrations may wish to consider if the actions identified in these areas are appropriate for them and, if so, how to take them forward. More work will be needed to identify the implications of some of the proposals within the devolution context.

The report does not seek to amend existing legislation pertaining to the Disability Discrimination Act (1995) and the new Draft Disability Discrimination Bill

The Disability Discrimination Act (DDA) and the new Disability Discrimination Bill are described in section 1.3. The draft bill represents a significant step in extending civil rights and opportunities for disabled people. The existing and forthcoming legislation together form an important backdrop to this report, and are taken as a given for the foreseeable future. The same is true of progress towards a new Commission for Equality and Human Rights (CEHR), which will bring disability together with other aspects of the equality and diversity agenda (see section 1.3).

1.3 Recent developments in legislation and policy

There have been many important policy developments that should have a positive impact on disabled people's life chances

This report builds on the considerable progress that has been made in recent years.

- **Disability Discrimination Act 1995** – the 1995 DDA Act was the first anti-discrimination legislation specifically about disabled people. It enshrines in law disabled people’s rights to participate in civil society through application to employers, service providers, landlords and schools and colleges. Some elements became law for employers in December 1996. Others were introduced over time³.
- **The Disability Discrimination Act (Amendment) Regulations 2003** extended the DDA to firms with fewer than 15 employees and provided new protection for disabled fire-fighters, police, office holders, barristers, partners in partnerships and people seeking vocational qualifications. The provisions were brought into force on 1 October 2004.
- **The Draft Disability Discrimination Bill** will amend the Disability Discrimination Act 1995 (DDA) in various ways. It introduces a wide range of measures recommended by the Disability Rights Taskforce. A particularly significant amendment is a new duty placed on the public sector ‘to promote disability equality’ (this parallels the Race Relations Amendment Act)⁴.
- **The Commission for Equality and Human Rights** – the Government announced in October 2003 plans to set up a new Commission for Equality and Human Rights. It is intended to bring together the work of the three existing equality commissions – the Commission for Racial Equality (CRE), the Disability Rights Commission (DRC) and the Equal Opportunities Commission (EOC) – and take responsibility for new laws outlawing workplace discrimination on the grounds of age, religion or belief, and sexual orientation.
- **The Supporting People** programme was launched on 1 April 2003 to support vulnerable people, including disabled people,

³ For service providers (e.g. businesses and organisations):

- since December 1996 it has been unlawful to treat disabled people less favourably than other people for a reason related to their disability;
- since October 1999 they have had to make reasonable adjustments for disabled people, such as providing extra help or making changes to the way they provide their services; and
- from this year (2004) they have had to make reasonable adjustments to the physical features of their premises to overcome physical barriers to access.

For employers, those with fewer than 20 employees were excluded. This exclusion threshold was changed to 15 employees in December 1998. From 1 October 2004, the small exclusion was ended.

For education providers, new duties came into effect in September 2002 under Part IV of the DDA amended by the Special Educational Needs and Disability Act (SENDA).

⁴ The draft bill will also amend the DDA by: covering transport vehicles in Part 3; extending duties on reasonable adjustments to landlords and others who manage rented premises; covering larger private clubs; extending the rights of disabled local councillors; and bringing people with HIV, cancer and multiple sclerosis into scope.

to sustain or improve their ability to live independently. The programme has for the first time allowed the provision of housing-related support services to be properly planned at the local level, allowing services to reflect local needs and priorities and to be better integrated with other local services.

- **The Government's Strategy for SEN (Special Educational Needs)** – "Removing Barriers to Achievement" was launched in February 2004. It sets out the Government's vision for enabling children with special educational needs to realise their potential. And it establishes a programme of sustained action over a number of years to support early years settings, schools and local authorities in improving outcomes for children with SEN, within the context of the wider programme to improve outcomes for all children described in "Every Child Matters".
- **The Children's National Service Framework** – published jointly by the Department of Health and the Department for Education and Skills in September 2004, the NSF sets standards for services for disabled children and their families against which services will in future be inspected.
- **"Pathways to Work"** has been designed to improve work opportunities for those on Incapacity Benefit (IB). It sets out a strategy for encouraging and assisting those people moving onto Incapacity Benefit to return to work. The aim is to enable people to overcome obstacles to work, by focusing on their capabilities and thereby challenging the belief that people with health conditions are incapable of doing any work. It has been piloted in three areas since October 2003, and a further four areas since April 2004.
- **The New Deal for Disabled People (NDDP)** aims to help people on disability and health-related benefits move into and keep paid work through a network of Job Brokers.
- **"Building on New Deal (BoND):** Local solutions meeting individual needs" is the Government's strategy for the evolution of welfare to work policies and programmes.
- DWP has developed a **"Framework for Vocational Rehabilitation"**, published in October 2004, which pulls together information about best practice, research and available capacity, and is in support of progress along the roadmap towards IB reform.
- **Vision for Adult Social Care** – the Social Care Institute for Excellence (SCIE) has been helping the Government to consult with people who work in and who use social care services on the future of adult social care. The results were published in August 2004,

and are feeding into a government Green Paper due to be published later this year.

- **Mental Capacity Bill** will create a new statutory framework for making decisions about financial, health and social issues on behalf of people who lack mental capacity.
- DH has published the **White Paper “Choosing Health”** which sets out actions to prevent injury, illness and impairment, and initiatives to assist recovery for full participation in community and working life.

1.4 Definitions and concepts

What is disability? And who are disabled people?

Disability is subject to a number of different definitions

Disability is defined for this project 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.

Disability is distinct from both:

- **impairment** – a long-term characteristic of an individual which affects their functioning and / or appearance and may give rise to pain, fatigue, communication difficulties, etc; and
- **ill health** – the short-term or long-term effect of disease or sickness⁵.

Many people who have an impairment or ill health would not consider themselves to be disabled.

For young people, “**Special Educational Needs**” is another important concept. This term was first recognised in the 1981 Education Act and includes children with “a learning difficulty, which may be the result of a physical or sensory disability, an emotional or behavioural problem, or developmental delay”.

Box 1.1: The difference between disability, impairment and ill health

Most people have some form of impairment or ill health at some point in their lives. This may be temporary (e.g. pneumonia) or permanent (e.g. blindness, rheumatoid arthritis). Many people with an impairment or ill health do not necessarily think of themselves as disabled. But many of these people would be defined as disabled under a range of measures – and the extent of their disadvantage will be determined by the barriers they face and by the support they receive for their individual needs:

- An individual may be hard of hearing. Someone with this form of impairment is disabled because communication generally relies on being able to hear effectively. But if this person has access to a digital hearing aid, the extent

⁵ The distinction between impairment and ill health is not always clear-cut. Alternative terminology speaks of “long-term conditions” or “chronic disease”, both of which focus primarily on permanent ill health.

of their disadvantage will be relatively small.

- Another person may have Multiple Sclerosis. This is their impairment, and if they are a wheelchair user, they may be disabled because public transport is inaccessible to them. They may also develop ill health, because they are more susceptible to adverse effects from colds or the flu. Ill health may also result from disabling barriers: for example, lack of an appropriate wheelchair cushion may lead to pressure sores.

The phrase “disabled people” can therefore include anybody who is disadvantaged by the way in which the wider environment interacts with their impairment or ill health. In practice, “disabled people” are defined in different ways to include or exclude different groups. There is no single agreed definition.

Box 1.2: There are large numbers of disabled people, and important trends changing the characteristics of disabled people

- According to some definitions there are currently around 11 million disabled adults and 770,000 children in the UK, equivalent to 24% of the adult population and 7% of all children.⁶
- One in twenty children under 16-years old is disabled and there

are increasing numbers of children with complex needs⁷.

- Among adults, trends in impairment show that an increasing number of people report mental illness and behavioural disorders, while the number of people reporting physical impairments is decreasing.
- The prevalence of impairment differs across ethnic groups. Black and minority ethnic groups are less likely to report impairments than the white population, but they are more likely to experience poor outcomes if they are disabled.
- Increasing life expectancy coupled with limited improvements in healthy life expectancy means an increase in age-related impairment and disability.

But it is clear that:

- this is not a precisely defined group of people;
- there is considerable heterogeneity within the population of disabled people; and
- the population of disabled people is not the same as those claiming disability related benefits. Therefore, generalisations about disabled people are unhelpful.

⁶ ONS (2004) “Living in Britain: Results from the 2002 General Household Survey”

⁷ Family Resources Survey G.B. (2002-03), DWP

For example, in considering employment, the primary focus here is on disabled people who are out of work. Many of these people – but not all – are claiming incapacity-related benefits. But many people claiming incapacity-related benefits would not consider themselves to be disabled.

Box 1.3: The heterogeneity of the disabled population

There are three main sources of the heterogeneity of disabled people:

- **Impairment type** – including variation by severity, duration, age of onset, and the evolution of the impairment over time. The issues faced by a person born blind will be different from those faced by a person who develops a heart condition in their 50's – but both may be disabled.
- **Socio-demographic characteristics** – including variation by social class, region, ethnicity, age or gender. The issues faced by a disabled child born to a lone parent in Tower Hamlets will be different from those faced by a disabled child born to a wealthy family in Guildford.
- **Impact of different barriers** – every disabled person will face a different combination of attitudinal, physical and socio-economic barriers.

1.5 Project participants and processes

Composition of the Strategy Unit team

The project was carried out by a multi-disciplinary team (see Annex B), including team members with experience in economics, social policy, local government and with expertise in disability issues.

Links with other government activities and external groups

The team has had regular meetings with the study's Sponsor Minister, Maria Eagle (Minister for Disabled People, Department for Work and Pensions). The team has also met regularly with the Project Advisory Group. The group, chaired by Maria Eagle, was made up of Ministers, external experts and civil servants. In addition, the SU appointed expert advisory groups to assist with different aspects of its analysis. Full details are given in Annex B.

Throughout the study, the team has gathered external input. It has held a number of meetings and discussions with a wide range of stakeholders and experts from among disabled people and their representatives, as well as other interested organisations (see Annex C). The team has also had regular contact with representatives from key government departments with an interest in this area, as well as with representatives from the devolved administrations.

In addition to contact with officials,

the team organised extensive focus group consultations which included disabled people and carers to support the development of the policy options (see Annex D). Written responses were received from just under 100 correspondents including individual responses and from a range of organisations (see Annex E).

1.6 Phases of the study

Phase one of the project was an extended scoping phase, running until early February 2004. The Strategy Unit held meetings with representatives of disabled people, service providers, government departments and other organisations. The Strategy Unit also reviewed the literature and evidence base on disabled people's life chances. The purpose of this phase was to establish an overview of the evidence and identification of main messages. At the end of this phase, the Strategy Unit proposed some areas for more detailed analysis in Phase Two of the project. This work highlighted the importance of transition points, and cross-cutting themes around policy design and delivery.

Phase two of the project was an analytical phase, during which the SU undertook detailed analysis of the issues within the framework identified in phase one. During this phase the SU met a number of stakeholders and experts from inside and outside government. At the end of this phase, the SU published for

comment an Interim Analytical Report⁸. The report drew together the evidence of the disadvantages that disabled people experience, and provided an analysis of the key barriers, an assessment of the current policy map, and outlined some alternative approaches.

Phase three of the project, the policy recommendation phase, ran through the summer and involved extensive consultation through focus groups, expert groups and bilateral meetings – as well as written responses. This phase saw the development of the vision, strategy and specific recommendations included in this report.

1.7 Next steps – implementation of the report

Government collectively will be responsible for implementation

This report has been accepted by the UK Government and a process of implementation has been agreed. This process will involve all government departments with responsibility for policies which impact on disabled people's life chances. The day-to-day lead for implementation will, in due course, transfer to the new Office for Disability Issues (see Chapter 8). Accountability for the implementation of the report will be through a Ministerial Group, reporting on an annual basis to the Prime Minister. As implementation is taken forward, all departments will ensure that there is appropriate opportunity to comment on the

⁸ The report remains available on the Strategy Unit website at www.strategy.gov.uk

details of policy changes.

There is a three-month opportunity to provide feedback to the Strategy Unit on this report

The Strategy Unit would welcome feedback on this report and on the project as a whole. Feedback should be sent to:

Disability@cabinet-office.x.gsi.gov.uk

Or to:
Strategy Unit Disability Team
Cabinet Office
4th Floor, Admiralty Arch
The Mall
London SW1A 2WH

The deadline for responses is Friday 15th April 2005.

The report is available in a range of alternative formats.

Please contact the Strategy Unit at 020 7276 1881 or strategy@cabinet-office.x.gsi.gov.uk for further information.

1.8 Structure of the report

The remaining chapters of this report cover the following issues.

Chapter 2 draws on material from the Interim Analytical Report and from other sources in order to establish the extent of the disadvantage faced by disabled people, the costs of that disadvantage, and how the picture is changing over time.

Chapter 3 sets out how and why government should address the problems identified in Chapter 2 to improve the life chances of disabled people. The chapter sets out the vision that government has committed to achieve and the key goals that need to be reached.

Chapter 4 on independent living puts forward arguments for enabling disabled people to fulfil their roles and responsibilities as citizens.

Chapter 5 looks at early years provision and family support.

Chapter 6 considers transition to adulthood for disabled young people.

Chapter 7 sets out an overarching vision that disabled people must be empowered, supported and well-equipped in order to enhance their employability. It also proposes measures to engage employers in recruiting and retaining disabled people.

Chapter 8 provides an assessment of how the programme of reform set out in previous chapters can be delivered effectively, focusing in particular on the application of the public service reform agenda to the services provided to disabled people.

Chapter 9 on implementation sets out recommendations for improved arrangements in the design and delivery of provision led by a new Office for Disability Issues.

Annexes provide further details on the preparation of this report and background analysis of some key issues. Annexes A to C are included in this report, and cover:

- the role of the SU (Annex A);
- the Project Team, Sponsor Minister, expert advisory and working groups (Annex B); and
- organisations consulted and submissions received (Annex C).

Annexes D to F are published separately from the main report, and should be seen as background accompanying analysis. They can be found at www.strategy.gov.uk.

- A review of focus group consultations (Annex D).
- A review of the main messages from responses to the analytical report (Annex E).
- The results of a literature review of the specific issues faced by disabled people with the most complex needs (Annex F).

Chapter 2: The Current Situation and its Causes

Summary

The population of disabled people is large – about 11 million adults and 770,000 children in the UK, using the widest survey definition. This equates to more than one-in-five adults, and around one-in-twenty children – though many of these would not see themselves as disabled, and many do not claim disability-related benefits or use services aimed specifically at disabled people.

The population of disabled people includes wheelchair users, blind people and Deaf people – these are an important minority of the total, but the majority of disabled people have other (often less visible) impairments. Among adults, trends in impairment show increasing numbers reporting mental illness and behavioural disorders, while the number of people reporting physical impairments is decreasing. Although older people are more likely to be disabled than younger people, trends show an increasing number of children reported as having complex needs, Autistic Spectrum Disorders or mental health issues.

Disabled people are doing less well than non-disabled people across a wide range of indicators and opportunities. Disabled people are more likely to achieve lower outcomes in terms of employment, income and education. They are more likely to face discrimination and negative attitudes, and often experience problems with housing and transport.

Poor outcomes are both a cause and a consequence of disability. Low incomes, non-employment, and low education all independently increase the probability of someone becoming disabled. Many of these risk factors are amenable to policy intervention. Often the onset of ill health or impairment deepens pre-existing disadvantage.

The extent of the disadvantage is especially acute for some specific groups. For example, although some black and minority ethnic groups are somewhat less likely to report impairment than the white

population, they are more likely to experience poor outcomes if they are disabled. People with mental health conditions or learning difficulties also face particularly poor outcomes.

The disadvantage faced by disabled people imposes significant economic and social costs – on disabled people, on their families and friends, on the wider community and on the economy. Instead of being empowered to participate and be included, too many disabled people are left to depend on benefits and government support.

This introductory chapter provides an overview of the evidence on disabled people's life chances. Section 2.1 outlines the scale of the challenge faced. The relationship between disability and life chances is discussed in Section 2.2. Section 2.3 then turns to examine the costs of disadvantage for disabled people, their families, the economy and wider society.

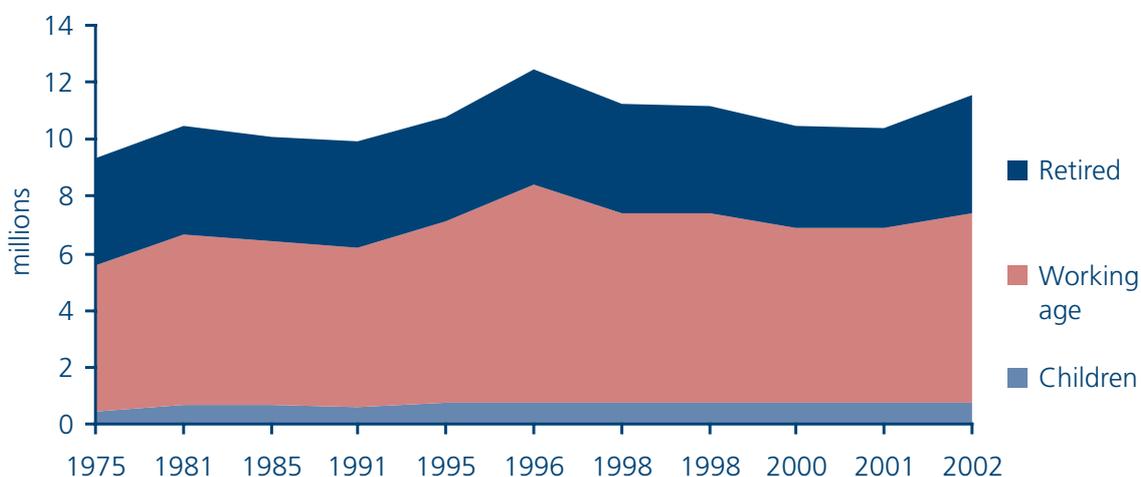
2.1 The scale of the challenge

There are currently around 11 million disabled adults in the UK, equivalent to 21% of the population⁹.

Over the last 30 years there has been an increase in the number of people reporting an impairment

Since 1975, the fastest growth in numbers has been for children – from 476,000 disabled children under the age of 16 in 1975, to 772,000 in 2002. This represents

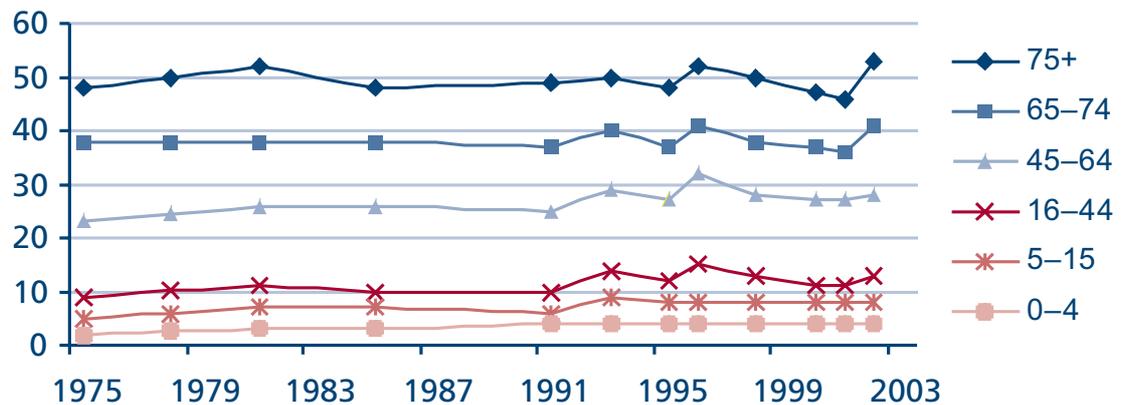
Figure 2.1: Number of people who reported a limiting long standing illness or disability by age, UK



Source: ONS (2004) Living in Britain: Results from the 2002 General Household Survey

⁹ONS (2004) "Living in Britain: Results from the 2002 General Household Survey"

Figure 2.2: Percentage of the UK population who reported limiting longstanding illness or disability by age



Source: ONS (2004) Living in Britain: Results from the 2002 General Household Survey

an increase of 62%. Possible explanations include increasing prevalence of impairment among children, children with complex conditions surviving longer, increased diagnosis, increased reporting and/or overall increases in the population. Over the same period the number of adults reporting impairment has increased by 22% from 8.7 million to 10.7 million people.

One in twenty children under 16-years-old is disabled and there are increasing numbers of children with complex needs

Evidence suggests that the numbers of children with complex and significant needs appear to be increasing. Increases of this type are partly associated with medical

advances enabling severely disabled children to survive infancy and to live longer. One study estimates an 11% increase in paediatric artificial feeding at home between 2001 and 2002, which is associated with home delivery and support services¹⁰.

There has also been an increase in the likelihood of diagnosis and/or prevalence of both Autistic Spectrum Disorders and mental health issues in young children. The Medical Research Council states that Autistic Spectrum Disorders (ASD) affect approximately 60 in every 10,000 children under 8-years-old, while narrowly-defined ASD affects 10-30 in every 10,000 children¹¹. These estimates "make autism spectrum disorders far more common than was previously recognised"¹².

¹⁰British Artificial Nutrition Survey (2004) 'Trends in artificial nutrition support in the UK between 1996 and 2002'.

¹¹Medical Research Council (2001) 'MRC Review of Autism Research: Epidemiology and Causes'.

¹²MRC (2001).

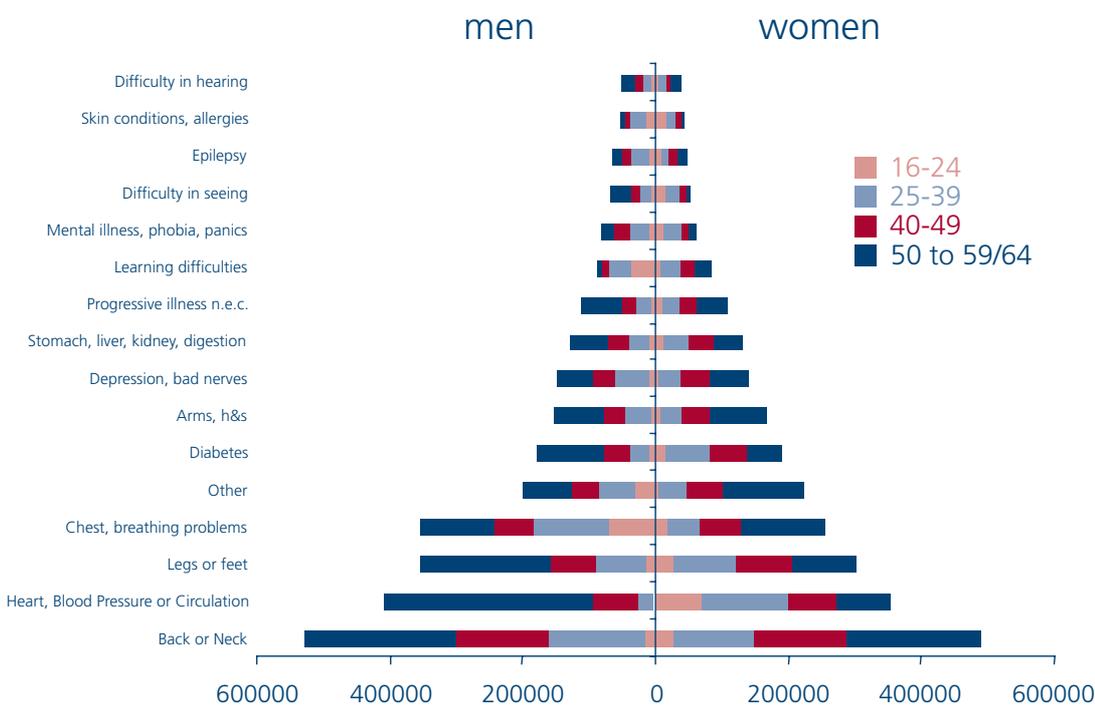
Patterns of impairment differ between disabled adults and children

Definitions of disabled people typically cover people with a wide range of impairments and ill health. As Section 1.4 has observed, this is one reason why the population of disabled people is so diverse. In addition to wheelchair users, blind people and Deaf people, the population of disabled people can include people with long-term progressive conditions such as

Multiple Sclerosis, HIV /AIDS or cancer from the point at which adverse effects emerge¹³, as well as people with impairments as wide-ranging as back pain, depression and heart conditions.

Disabled young people have a different impairment profile from adults – they are more likely to have a learning difficulty, and initial onset of mental health problems often occurs in young adulthood¹⁴.

Figure 2.3: Number of disabled adults by gender, age and impairment, GB



Source: Annual Local Area Labour Force Survey 2001–02

¹³The Government has announced that the new Disability Discrimination Bill will bring those who have progressive conditions, but who do not yet experience significant impairment within the scope of the DDA. The Government will also use the bill to remove the requirement that a mental illness must be “clinically well recognized” before it can count as an impairment.

¹⁴SEU (2004) *Mental health and social exclusion*. The Stationery Office. Young Minds found between one in four and one in five young people experience mental health problems by age 16.

For disabled adults, the pattern of impairment is broadly similar across gender. The most commonly reported impairments for both men and women are problems of the back or neck, the heart or circulation, legs or feet or breathing problems.

A higher proportion of women report depression or ‘other’ impairments. Fewer women than men report problems with their heart, blood pressure or circulation, diabetes, or report chest or breathing problems. For most impairments the prevalence increases with age – though men with learning difficulties are more likely to be in younger age groups,

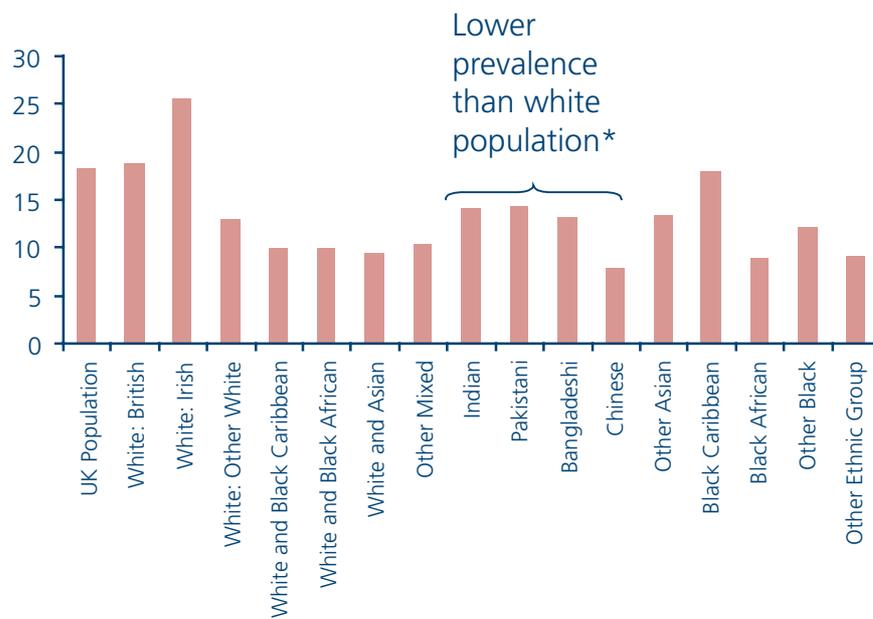
and men with depression or mental illness are most likely to be in the 25–39 age group¹⁵.

The disabled population is changing. Among adults, trends in impairment show that an increasing number of people report mental illness and behavioural disorders, while the number of people reporting physical impairments is decreasing¹⁶.

The prevalence of impairment differs across ethnic groups

Black and minority ethnic (BME) groups are less likely to report impairment than the white population. Differences in age structure account for much of this

Figure 2.4: Percentage of people reporting a limiting long-term illness in England and Wales by ethnic group



Source: Census 2001, ONS

* Statistically significant difference from the white British population after controlling for age.

¹⁵ Annual Local Area Labour Force Survey 2001–02.

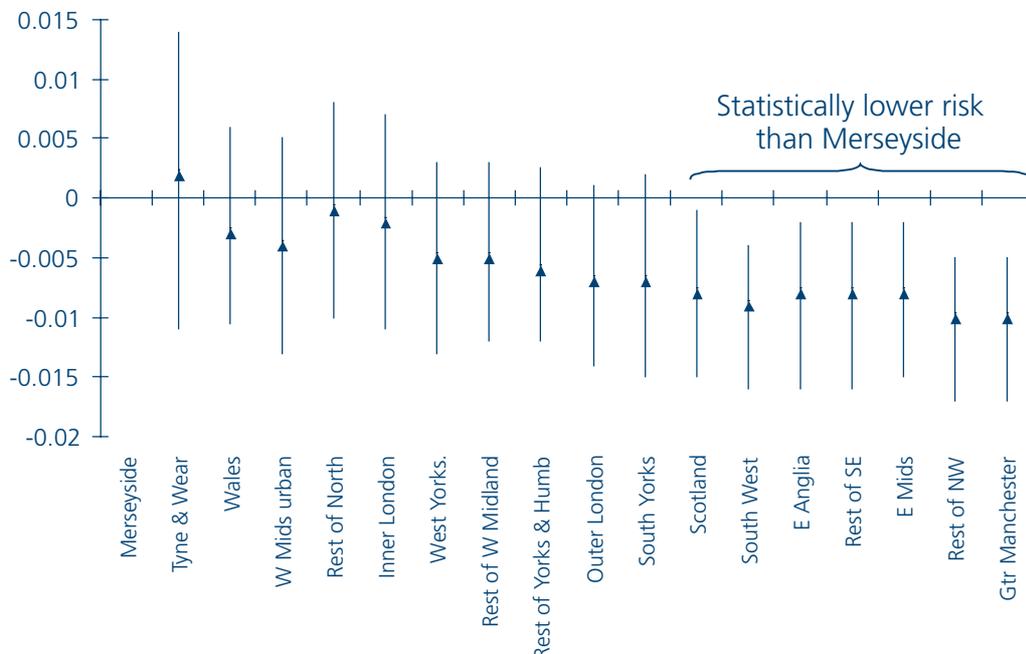
¹⁶ DWP (2003) Incapacity Benefits dataset, 5%.

variation in prevalence, as in the UK BME groups tend to have a younger population structure. But even after controlling for this age effect, people of Indian, Pakistani, Bangladeshi and Chinese origin remain less likely to report that they are disabled. These lower rates may be influenced by cultural differences in self-reporting across ethnic groups¹⁷.

Despite the lower levels of reported impairments, evidence suggests that disabled people of BME origin are more likely to experience disadvantage¹⁸. Families from BME

groups with disabled children have a lower take-up of services, and often feel less informed or able to access the system. People from BME groups tend to present to mental health services later, sometimes following contact with the criminal justice system. They may experience discrimination both on grounds of health status and ethnicity in seeking employment. A high proportion of the BME population lives in deprived areas and fall into disadvantaged groups – where a higher incidence of impairment would be expected¹⁹.

Figure 2.5: Variation in the risk of becoming disabled by region, controlling for age, employment status and occupation



Source: Burchardt (2003) using BHPS. Risk is given relative to Merseyside. The arrow indicates the average risk of a person within that region becoming disabled in any one year, the length of the line indicates the 95% confidence intervals.

¹⁷There is some difference in prevalence of specific impairments across ethnic groups, however sample sizes are too small for such differences to be reported in any meaningful way.

¹⁸Mental Health and Social Exclusion (2004) Social Exclusion Unit.

¹⁹Some of these issues are explored in Annex F to this document.

There are some regional differences in the prevalence of disability

Regional differences in the risk of becoming disabled do exist, but these do not show a systematic pattern. Links with regional de-industrialisation are not clear, as areas such as Merseyside show high risks of onset of impairment and/or ill health while the risk in nearby Greater Manchester is significantly lower.

The population of disabled people is distinct from the population claiming disability-related benefits

3.08 million people claim some form of disability-related benefit^{20,21}. There are a number of different benefits, both specific and generic, that disabled people may receive. This report is primarily about disabled people, rather than those claiming disability-related benefits. There are significant overlaps between these two groups, but there are also significant differences.

Table 2.1: Types of benefits and tax credits for disabled people

Extra costs benefits

Help with the disability-related extra costs of severely disabled people

- Disability Living Allowance (DLA)
- Attendance Allowance (over SPA)

Earnings replacement benefits

Provide an income for people who are not in work

- Jobseeker's Allowance (JSA)
- Incapacity Benefit (IB)
- Severe Disablement Allowance (now subsumed into IB)

Means-tested benefits and tax credits

(i) provide a minimum income level;
(ii) help low income people with housing costs
+ additional premiums for disabled people

- Income Support (IS)
- Working Tax Credit
- Disabled child element of Child Tax Credit
- Housing Benefit
- Council Tax Benefit

Compensatory benefits

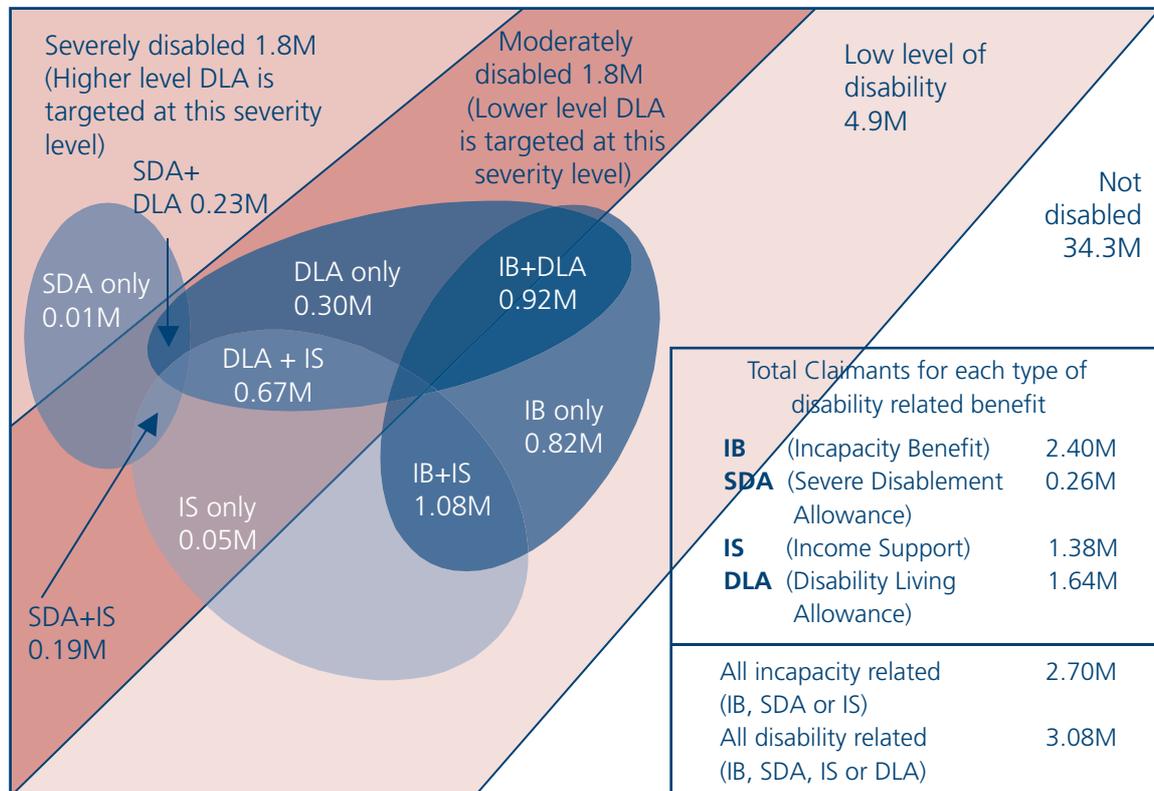
Compensate people who became disabled as a result of military service or their employment

- War Disablement Pension
- Industrial Injuries Disability Benefit

²⁰DWP (2004) Client Group Analysis.

²¹"Disability-related benefit" here refers to any benefit received because the individual has an impairment. "Incapacity-related benefits" are a subset of disability-related benefits, and refer to any income replacement benefit that someone with an impairment receives because of their impairment – specifically this includes incapacity benefit (IB) payments, incapacity benefit credits, income support (IS) on the grounds of incapacity and severe disablement allowance (SDA).

Figure 2.6: GB adult population by impairment severity (1996/97) and benefit receipt (2004)²²



Note: Data on numbers of people claiming three or more benefits is unavailable. This figure is a stylized picture of benefit reciprocity against the total disabled population. It is not drawn to scale.

Source: Family Resources Survey – Disability follow-up, 1996/97 and DWP (2004) Client Group Analysis.

In particular, in considering employment, the primary focus here is on disabled people who are out of work. Many of these people – but not all – are claiming incapacity-related benefits. And many people claiming incapacity-related benefits would not consider themselves to be disabled. Unfortunately the available data does not always allow us to differentiate between these groups.

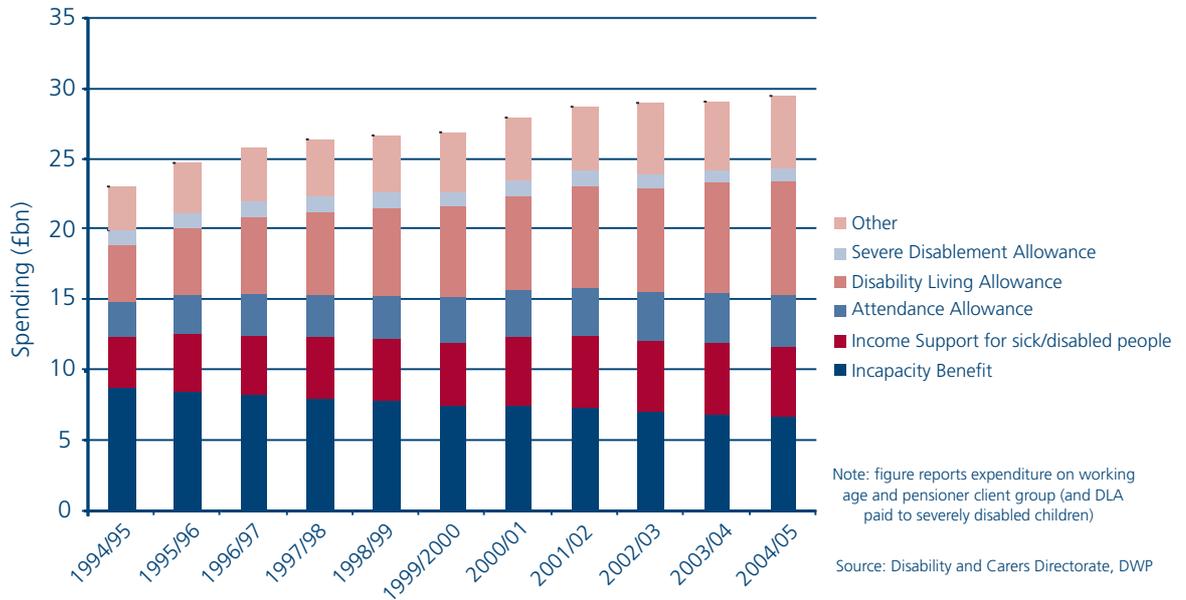
There has been a significant growth in government spending on disability benefits over the last 20 years

The number of incapacity-related benefit claimants has tripled since 1979²³. Currently 2.7 million people of working age claim incapacity-related benefits compared with 0.8 million JSA claimants, and 0.8 million lone parents receiving income support.

²²The most recent available data on severity is from the Family Resources Survey Disability follow-up in 1996/97 (all adults are included, including those over pension age). This tells us that 58% of disabled people experience a low-level impairment and 21% have a moderate impairment.

²³This excludes IB short-term lower cases.

Figure 2.7: Real spending on disability benefits (2004/05 prices)



Source: DWP (2004).

Note: 'Other' is Industrial Injuries Benefit and Payments to short and long-term sick and disabled people of: Community Charge/Council Tax Benefit, Housing Benefit and Discretionary Housing Payments and Income Support for under-60s excluding unemployed people. War disablement pension is excluded as consistent data is unavailable. Tax Credits are also excluded.

Government spending on disability benefits has increased in real terms over the last 10 years, and currently stands at £29.5 billion (2004/05 prices). This is due primarily to an increase in the numbers of people receiving disability living allowance and income support (with a disability premium). Spending on incapacity benefit has been falling since 1994/95, reflecting a fall in numbers receiving the benefit.

2.2 Disability is linked to life chances

Box 2.1: The reality of being a disabled person in 21st century Britain

A young man developed Multiple Sclerosis and as a result lost his job, his wife and his dignity. Someone was sent to get him out of bed at 10am, and to put him back to bed at 6pm – just so that they could fit in with the local authority carers' rota. He tried moving into a long-term residential home, but was very unhappy²⁴.

One father of two severely disabled children said, "I've had

²⁴ Source: SU consultation with disabled people and parents of disabled children

to put work on hold, which is absolutely crazy... I haven't had time to generate the business. If we had the right level of care, I would be out there running my business, employing people, paying tax²⁵."

Susan's son, David, was diagnosed with Autistic Spectrum Disorder when he was three years' old. Susan had to wait for four months after the diagnosis before she was given any information, or contacted by any services. Susan found it difficult to get hold of information, and, when she did, there was no-one available to talk it through with her²⁶.

Disabled people are doing less well than non-disabled people across a wide range of indicators and opportunities

Disabled people are more likely to achieve lower employment outcomes

Disabled people are less likely to be employed and more likely to be economically inactive²⁷ than non-disabled people. Only one in two disabled people of working age are currently in employment compared to four out of five non-disabled people²⁸.

The employment rate of disabled people is less than that of any other disadvantaged groups such as lone parents and black and minority ethnic groups²⁹.

Employment rates are much lower for disabled men between 40 and State Pension Age than disabled women of similar ages. Employment rates are also especially low for some groups of disabled people, such as those with mental health problems and learning difficulties³⁰.

Employment is beneficial for people. Not only does it provide financial benefits but it also boosts self-esteem, the opportunity to develop, socialise and build social networks. Employment provides people with a sense of dignity, self-worth and purpose. Disabled people out of employment may therefore lack these benefits.

Unemployment leaves permanent scars on individuals both financially and psychologically. A period of unemployment is found to reduce wages by about 6% on re-entry to the labour market in Britain, and after three years, individuals who return to work are earning 14% less than they would have received in the absence of unemployment³¹. There is also a strong relationship between unemployment and

²⁵ The Times, 29th June 2004

²⁶ Source: SU consultation with disabled people and parents of disabled children

²⁷ 'Economic inactivity' describes people who are not in the labour market. People who are economically inactive are neither in work nor seeking employment.

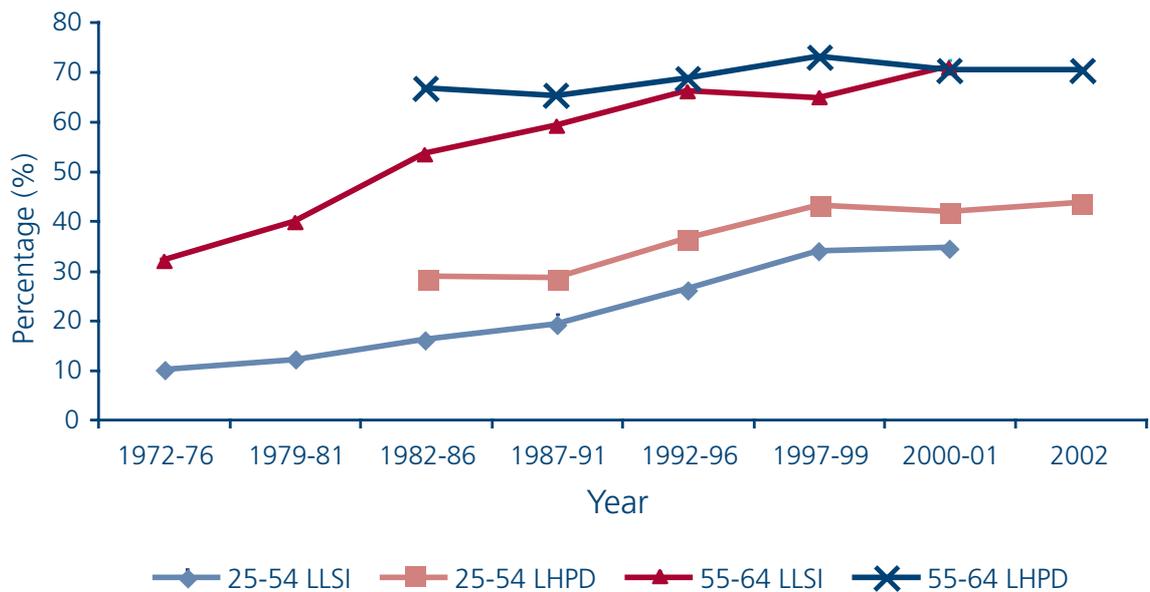
²⁸ Labour Force Survey 2002.

²⁹ Labour Force Survey 2002.

³⁰ The employment rates for those with learning difficulties percentages presented in the Labour Force Survey are far too small to be reported in a meaningful way.

³¹ Arulampalam, W (2001) "Is unemployment really scarring? Effects of unemployment experiences on wages", The Economic Journal, Vol 111 585-606.

Figure 2.8: Inactivity Rates among Men (%) by age with a limiting long-standing illness or a limiting health problem or disability 1972–2002



Source: Faggio and Nickell (2003); LLSI is a limiting long-standing illness. LHPD is a limiting health problem or disability.

worsening mental health, and ill health in general leading to premature death³².

Patterns across employment for disabled people are mirrored by patterns across economic inactivity

Despite the strong economy and improving labour market conditions since 1998, there has been an increase in the number of economically inactive people reporting a disability.

Currently, nearly half of all disabled people of working age are economically inactive compared with 15% of non-disabled people. If we wanted to increase the employment

rate of disabled people up to the current national average we would need to get almost 1.8 million more disabled people into work.

There are particular concerns around labour market inactivity amongst disabled young people. Disabled young people are considerably more likely than non-disabled people to be not in education, employment or training (NEET), particularly from age 19 when many will first transfer out of special school.

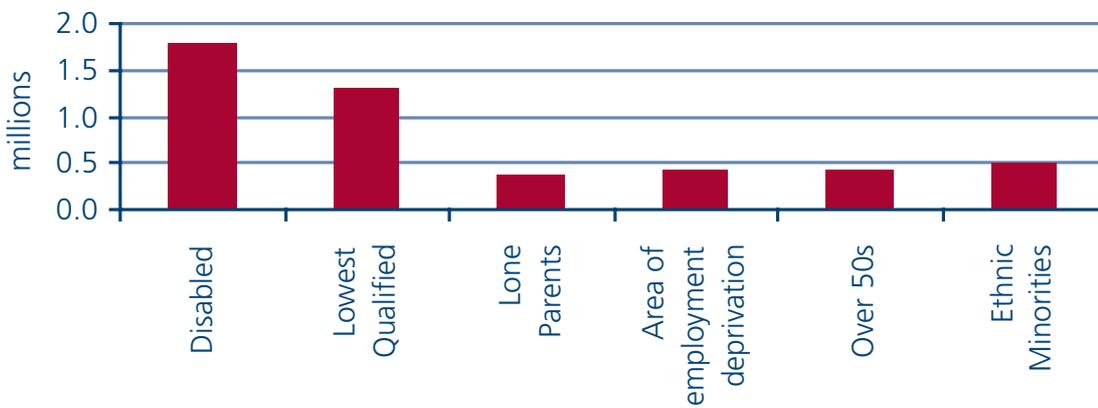
Levels of economic inactivity among disabled people vary with the severity of impairment. Half of those with middle severity rates report

³² Bartley, M (1994) "Unemployment and ill health: Understanding the relationships", Journal of Epidemiology and Community Health, Vol 48 333–337.

that they are permanently unable to work. In the age group 50–64, the majority of disabled men – even those who are moderately disabled – report that they are permanently

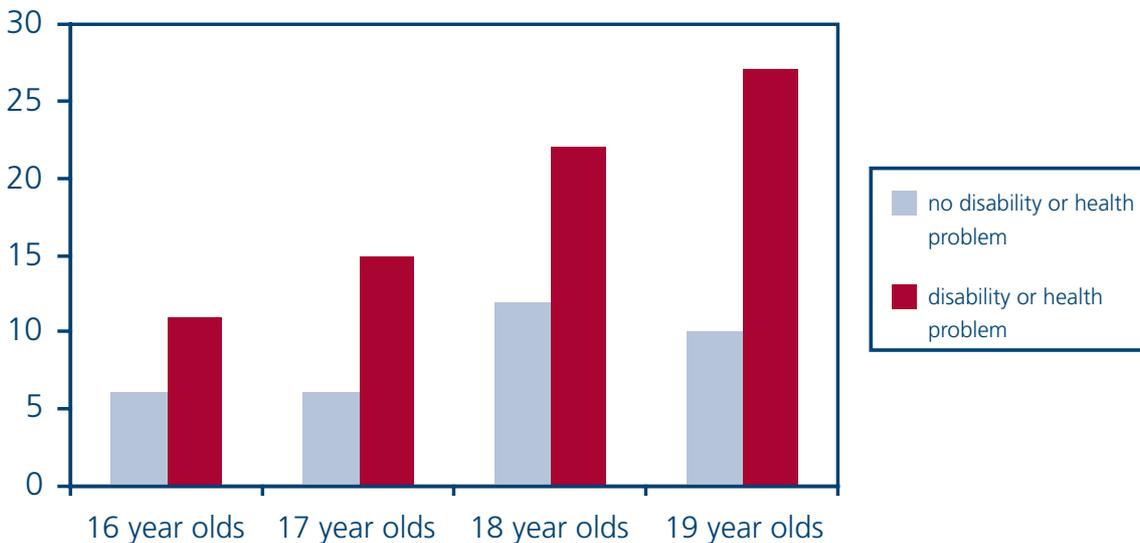
unable to work. A larger proportion of disabled women across all severities report themselves to be available but not looking for work.

Figure 2.9: Employment growth needed to reach current overall UK employment rate



Source: HMT (2003) Full employment in every region. There are substantial overlaps between the different groups.

Figure 2.10: Percentage of young people not in education, training or employment, by age and whether they have a disability or health problem



Source: The Youth Cohort Study (YCS) (2003) Cohort 10, Sweep 4.

Figure 2.11: Economic activity of men under 50 by severity category

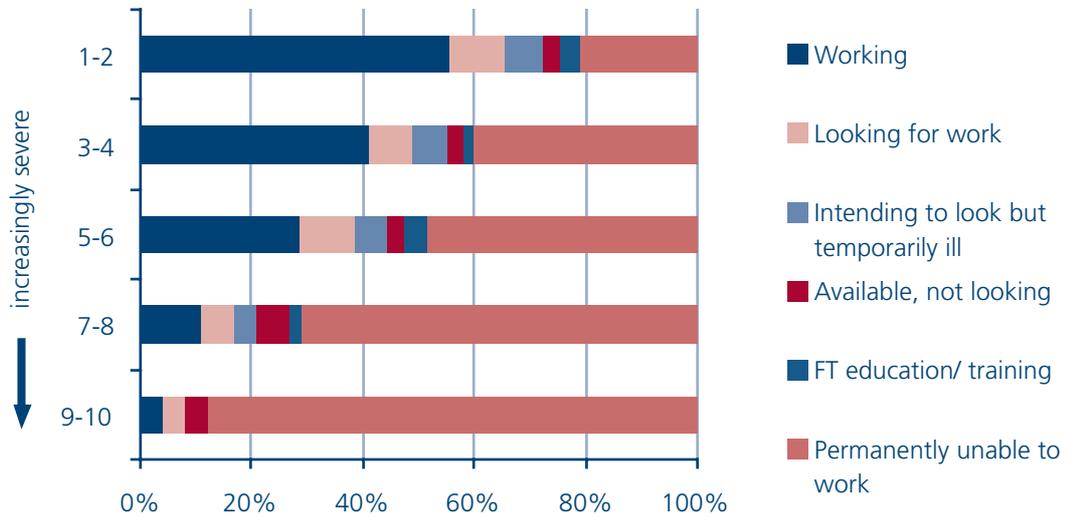
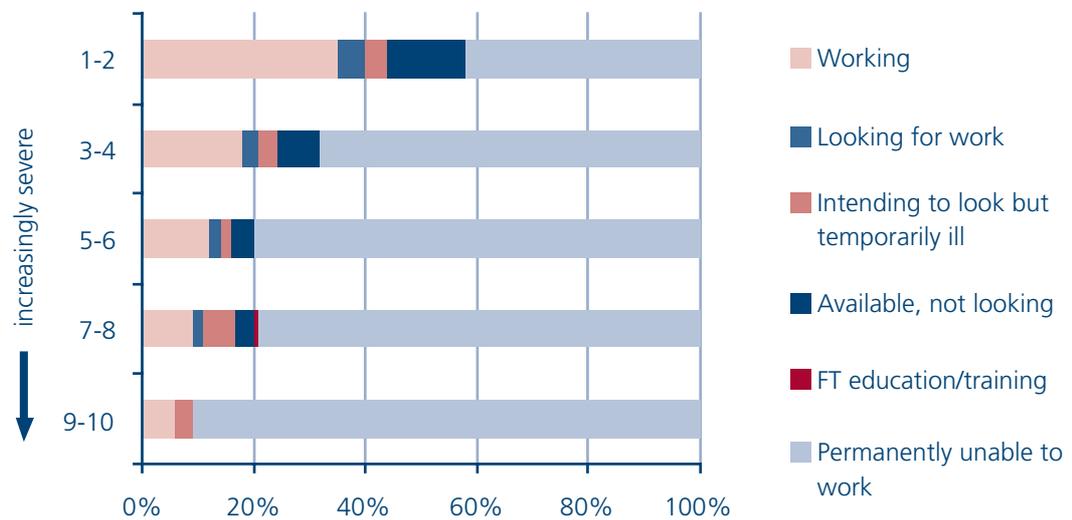


Figure 2.12: Economic activity of men aged 50–64 by severity category



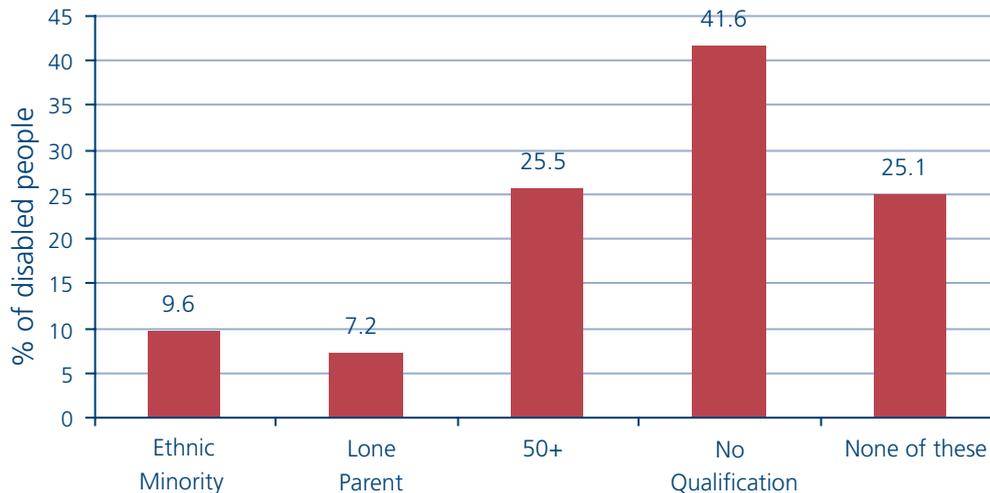
Source: Grundy, E, Ahlburg, D, Ali, M, Breeze, E and Sloggett, A (1999) "Disability in Great Britain: Results from the 1996-97 Disability Follow-up to the Family Resources Survey", Department of Social Security, Research Report 94.

Many disabled people experience multiple disadvantage

There are proportionately more disabled people who are older,

from poor social backgrounds and with lower levels of qualifications and skills.

Figure 2.13: Percentage of disabled people who experience some other form of labour market disadvantage



Source: DWP using Labour Force Survey (2002), unpublished.

Disabled people are more likely to live on lower incomes than non-disabled people

The income of disabled people is, on average, less than half that of non-disabled people. Even after direct taxes and benefit payments have been accounted for – disabled people still earn 30% less than non-disabled people³³. At the same time, the experience of impairment and disabling barriers can mean that disabled people have increased costs compared with their non-disabled peers.

Disabled people are more likely to live in poverty. 27% of individuals in households with one or more

disabled adults of working age have incomes below 60% of median income, compared with 20% of individuals in households with no disabled adults³⁴. Among workless households with children the majority have at least one disabled parent: children are more likely to experience poverty if there are disabled adults in their family³⁵.

Families of disabled children are more likely to live in poverty.

Twenty nine per cent of people with a disabled child in the household live in poverty, compared with 21% of households with no disabled children³⁶. Mothers of disabled children are seven times less likely

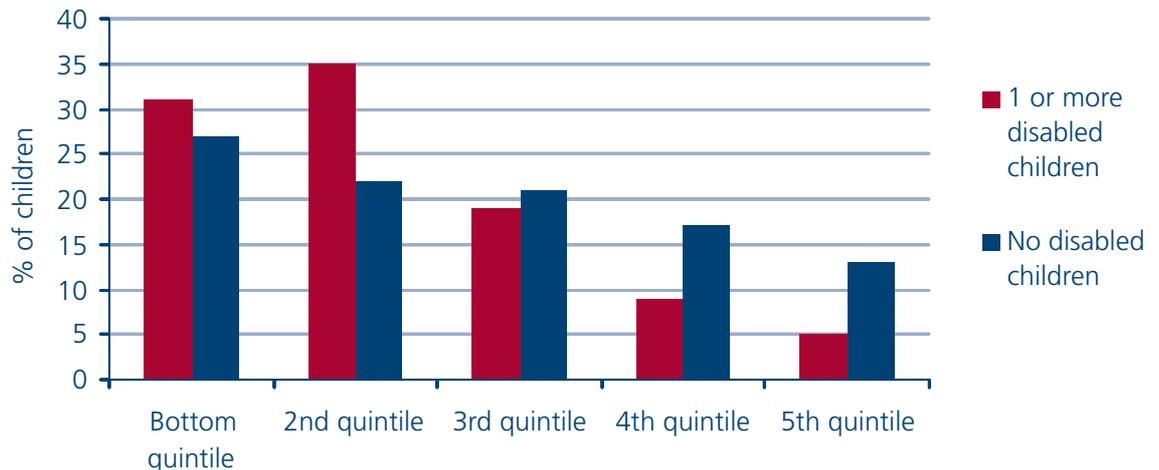
³³ Bardasi, E., S.P. Jenkins and J. Rigg (2000), "Disability, work and income: a British perspective", Working Paper No. 2000-36, Institute for Social and Economic Research.

³⁴ DWP (2003) "Households Below Average Income".

³⁵ Stickland, H. (2003) Disabled Parents and Employment. Background paper for the HMT/DWP Seminar held on 23 November 2003.

³⁶ DWP (2003) "Households Below Average Income".

Figure 2.14: Quintile distribution of income for households with and without disabled children



Source: Households Below Average Income (2003).

than mothers with non-disabled children to be able to get work, mainly because of a lack of childcare³⁷.

There are about 17,000 families in the UK with more than one disabled child and about 6,500 families with two or more severely disabled children. This is equivalent to well over 10,000 severely disabled children who live in a family with another severely disabled child³⁸. Research shows that these families are more likely to be single parent, unemployed, on income support, in semi-skilled or unskilled manual jobs and less likely to own their own home³⁹.

Disabled people are more likely to have no educational qualifications,

and less likely to have advanced qualifications

Education is a key driver of opportunity. High levels of education lead to higher employment and income levels and also to better social networks and improved life satisfaction. Low levels of education are associated with the opposite – increasing the probability that disabled people will experience poverty and social exclusion.

Disabled people may face discrimination and are more likely to be victims of hate crime and harassment

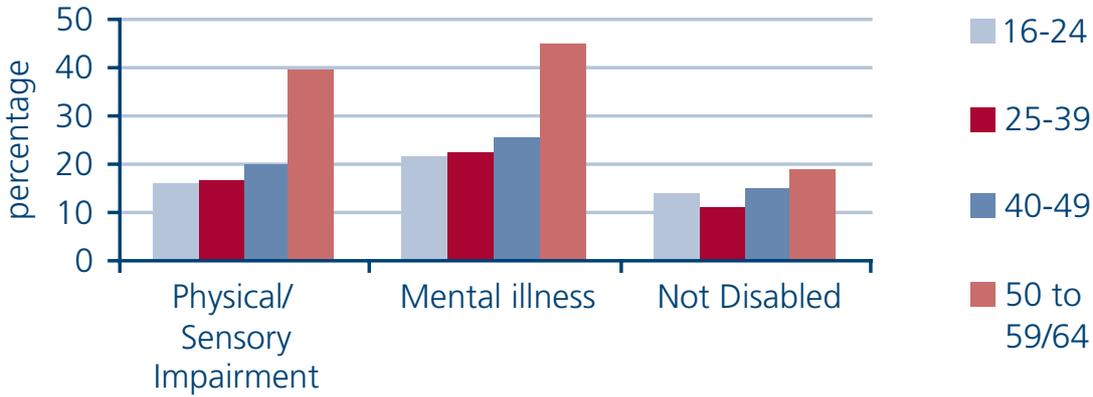
One in four disabled people have experienced hate crime or

³⁷ 3% of mothers with disabled children work full time, compared with 22% of mothers with non-disabled children (Family Fund Trust (2002) and General Household Survey (2002)) and 35% of non-working lone parents have disabled children (Daycare Trust (2001) Bridging the gap).

³⁸ Joseph Rowntree Foundation (1998) The number and characteristics of families with more than one disabled child. Based on Family Fund figures.

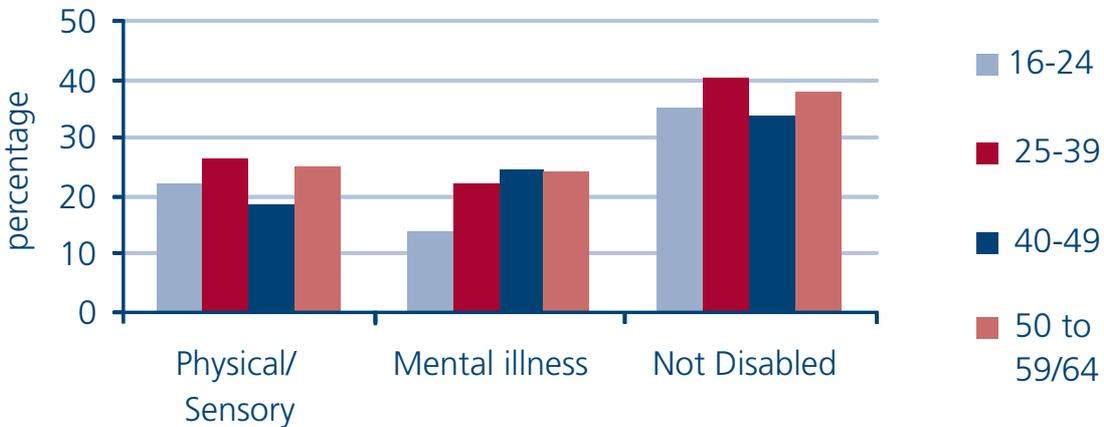
³⁹ Joseph Rowntree Foundation (1998).

Figure 2.15: Proportion of people with no qualifications (%) by impairment 2001–02



Source: Annual Local Area Labour Force Survey 2001 – 02.

Figure 2.16: Proportion of people with advanced qualifications (A-levels or higher) by impairment 2001–02



Source: Annual Local Area Labour Force Survey 2001–02.

harassment⁴⁰, rising to 47% of people with mental health conditions⁴¹. Eight in ten respondents to the Social Exclusion Unit’s “mental health and social exclusion” written consultation

reported stigma and discrimination to be the main driver of social exclusion. The majority of non-disabled people agree that disabled people do not have full equality with non-disabled people⁴², and that disabled people face prejudice⁴³.

⁴⁰ DRC (2003).
⁴¹ Mind (2003).
⁴² DRC (2003).
⁴³ Eurobarometer (2001).

Disabled people often experience problems with housing and with transport

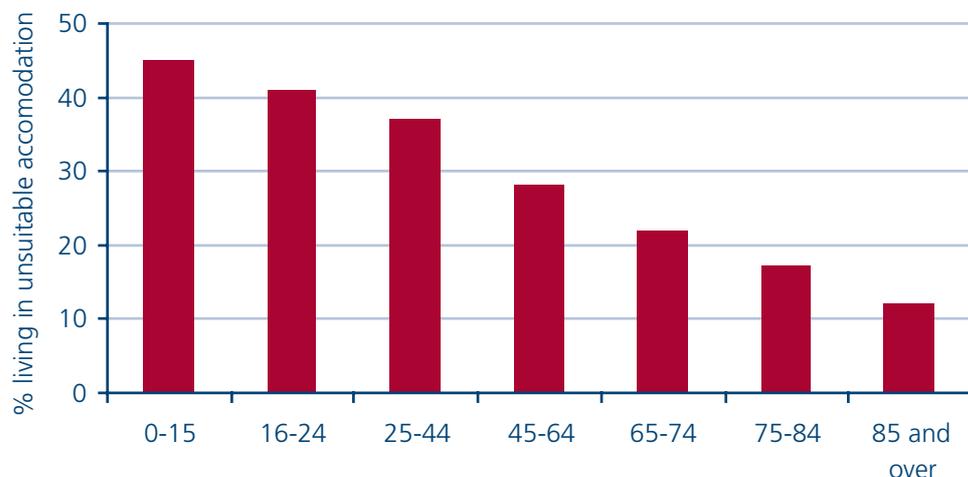
The economic disadvantages experienced by disabled people make it difficult for them to meet their housing needs through either buying or privately renting property. This increases dependency on social housing⁴⁴. Between 1997 and 2003 there has been a 44% increase in the number of homeless households in priority need because a household member has a physical impairment, and a 77% increase in the number of households where the priority need is someone with a mental illness⁴⁵.

Much of the housing stock is physically unsuitable for people with mobility or other impairments. These physical barriers do not just

affect people with mobility impairments. People with a wide range of conditions (asthma, heart conditions, mental health problems, and so on) can find that inadequate and inappropriate housing makes their condition worse.

Disabled people therefore often need alterations to housing which incur costs over and above that of non-disabled people. According to a survey of housing in England in 2000, a total of 181,000 households contain people 'with a serious medical condition or disability' whose accommodation is not suitable for them⁴⁶. Twenty-seven per cent said they could not afford to do these alterations and another 13% said they could not get a grant. 83,000 households were in the process of trying to move to somewhere more suitable⁴⁷.

Figure 2.17: Percentage of disabled people living in unsuitable accommodation



Source: ODPM (2003) Housing in England 2001/2.

⁴⁴ ODPM (2003) Housing in England 2002/3, the Stationery Office.

⁴⁵ ODPM (2004) English Survey of Housing.

⁴⁶ ODPM (2004) English Survey of Housing.

⁴⁷ Unpublished DWP paper.

Disabled people living in the privately rented sector were most likely to be living in housing unsuited to their needs, while owner-occupiers were most likely to report their housing was suitable.

Difficulties in accessing transport are a key component of wider social exclusion⁴⁸. Disabled people travel a third less often than the general public⁴⁹ and over a third of those who do travel experience difficulties, the most common being getting on or off trains or buses⁵⁰.

As a result of economic disadvantage, disabled people are disproportionately reliant on an affordable, accessible public transport system. However, people with physical and/or sensory impairments experience an unequal access to public transport as a result of a failure in the past to take their access needs into account when designing and building current provision. Significant physical barriers still exist but accessible public transport is being rolled out progressively and deadlines have been set by which all public transport will be accessible. The rate at which accessible buses and trains are coming into service varies

around the country. For example, while 90% of buses in London are now accessible, the national average is currently only around 30%⁵¹.

People with learning disabilities or mental health problems also experience barriers to accessing transport. If a person needs someone else to accompany them on public transport this increases the cost. Negative attitudes and harassment are also reported to be key barriers to getting out and about⁵².

Poor outcomes are both a cause and a consequence of disability

For some disabled people, poor outcomes arise after they become disabled. For example someone may be unable to do their job following the onset of impairment, or a child may receive poor education because their special education needs are not appropriately supported. However in many cases, the onset of impairment is preceded by disadvantage. Evidence shows that low incomes, non-employment, and low education all **independently** increase the probability of someone becoming disabled⁵³.

⁴⁸ Social Exclusion Unit (2003) Making the Connections: Transport and Social Exclusion, Social Exclusion Unit.

⁴⁹ Disabled Persons' Transport Advisory Committee (2002) Attitudes of disabled people towards public transport, DPTAC.

⁵⁰ DWP (2002) 'Disabled for life?' attitudes towards and experiences of disability in Britain.

⁵¹ Department for Transport (2003) Public Transport Statistics.

⁵² Strategy Unit consultation.

⁵³ Burchardt, T (2003) "Being and Becoming: Social exclusion and the onset of disability" Centre for the Analysis of Social Exclusion, London School of Economics CASE report 21 and Jenkins and Rigg (2003).

Figure 2.18: Probability of becoming disabled in any one year, by income quintile



Source: Burchardt (2003).

Many of these risk factors are amenable to policy intervention. Often the onset of ill health or disability deepens pre-existing disadvantage.

2.3 The costs of disadvantage

Disadvantage for disabled people has cost implications for the individual concerned, their families, the economy and wider society

Many of these costs can be quantified. For example, if disabled people had the same qualifications as non-disabled people, their gross income would be an estimated 9%

higher than its current level⁵⁴. The average annual costs of bringing up a disabled child are three times greater than for a non-disabled child⁵⁵, and there is significant variation within that average. However, just as important, are some of the intangible costs of this disadvantage.

⁵⁴ Annual Local Area LFS (2001/02) and Dearden (1998) Ability, Families, Education and Earnings in Britain, IFS Working paper 98/14.

⁵⁵ Gordon et al. (2000).

Table 2.2: Costs of high rates of economic inactivity amongst disabled people

	Tangible Costs	Intangible Costs
To disabled people	Forgone income net of taxes	Loss of quality of life Loss of self-esteem
To friends and relatives	Loss of private income net of tax if caring for disabled person	Loss of social life Pressure/anxiety
To the economy and wider society	Replacement worker training and hiring costs Output losses due to: <ul style="list-style-type: none"> • short/long-term absenteeism for mental and physical disability • premature mortality • reduced employment; and reduced employee efficiency. Reduced labour market flexibility	Lost benefits of having a diverse workforce

Chapter 3: Vision and strategy

Summary

There are strong grounds for government action to improve the life chances of disabled people. Supporting and empowering disabled people to help themselves will improve their participation and inclusion in the community, in the labour market and in wider society. This will deliver social and economic benefits for all of society – and all of society needs to be involved.

This report sets out an ambitious vision for improving the life chances of disabled people.

By 2025, disabled people in Britain should have full opportunities and choices to improve their quality of life, and will be respected and included as equal members of society.

This ambitious goal will require a step-change in the way we deal with the disadvantage faced by disabled people. This report sets out a radical long-term strategy to achieve this step-change, building on the considerable progress that has already been made.

Four key goals have been identified in this report as the most important determinants of disabled people's life chances:

- empowered citizens with choice and control over how additional needs are met;
- support for families with young disabled children;
- smooth transition into all aspects of adulthood; and
- improved employability.

In each of these areas, the Government's strategy for achieving the vision is based on:

- removing barriers to inclusion;
- meeting individual needs; and
- empowering people.

This chapter sets out how and why government should address the problems identified in Chapter 2 to improve the life chances of disabled people. Section 3.1 sets out the vision which government wants to achieve. Section 3.2 describes what society needs to look like to achieve the vision. The different rights and responsibilities of groups in society are set out in Section 3.3. Section 3.4 explains why government intervention is justified, and Section 3.5 follows by outlining the characteristics of successful government action to improve the life chances of disabled people. Finally, Section 3.6 sets out the wider context in which the report is based and specific issues that will need to be addressed to achieve the vision.

3.1 What outcomes does government want to achieve?

A step change is needed to improve the life chances of disabled people

The previous chapter has set out the current situation facing disabled people in the UK. The scale of the challenge is significant and needs a radical, long-term strategy for change if the situation is to improve.

This action will be building on good progress that has already been made since 1997 in legislation and in wider policy. But further improvements are needed in attitudes towards disabled people and in the opportunities and choices that disabled people have in their

lives. Many disabled people still have a poor quality of life, and are too often rendered dependent on benefits and care services by the attitudes and approaches of others. This lack of independence undermines disabled people's equality and rights as citizens. Sometimes this is a result of direct discrimination, including harassment and hate crime. More insidious is indirect discrimination, including institutional cultures that assume disabled people have less to offer than non-disabled people, or which fail to include disabled people.

This report sets out an ambitious vision

This report sets out an ambitious vision that government should strive for over the next 20 years. It provides an overarching goal to inform all government action with respect to disabled people, to improve their life chances and therefore their quality of life.

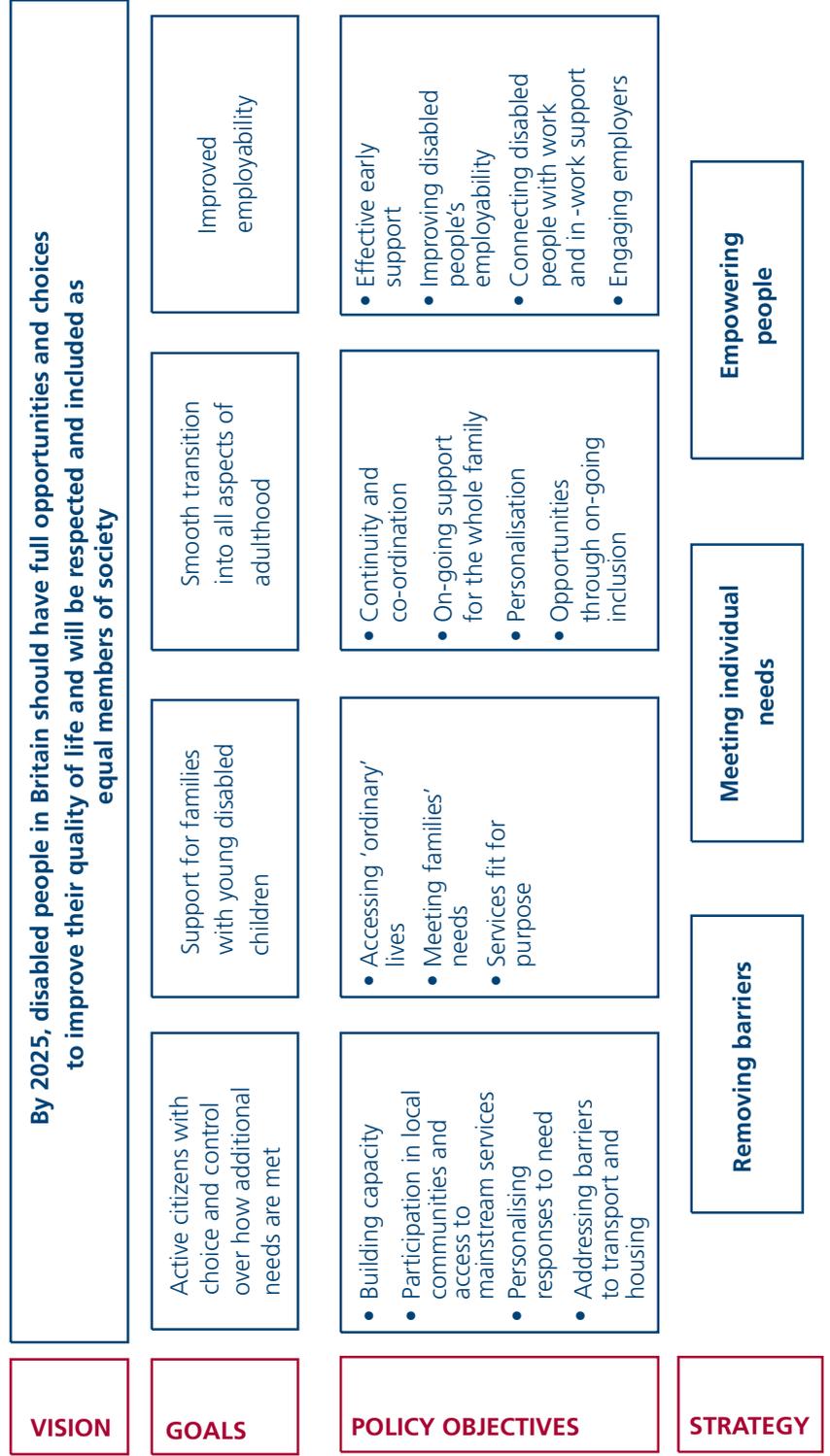
Box 3.1 The Government's vision

By 2025, disabled people in Britain should have full opportunities and choices to improve their quality of life, and will be respected and included as equal members of society.

This vision reflects the fact that there should be equality of opportunity for all people, irrespective of their needs. Different people will need different levels of support to access these opportunities, but the overall aim

Diagram 3.1: The vision, goals, policy objectives and strategy to improve the life chances of disabled people

This diagram sets out the overall vision and how it can be achieved through the four key goals. Each goal corresponds to a chapter in this report. Under each goal is a set of policy objectives which, together, will contribute to reaching the goal. The strategy is the basis for action and provides three principles for intervention to ensure that the objectives, goals and, ultimately, vision is achieved.



should be for disabled people to be able to take up opportunities to improve their own quality of life in a way that is comparable with non-disabled people.

The vision also reflects the basic right of disabled people to be respected as equal citizens and to be included in British society along with their non-disabled peers.

It is also important to note that wider aims set out by government – including reducing health inequalities, child poverty and gender inequality – would be undermined by a failure to address disability equality.

The diagram on the previous page sets out the overall vision and how this can be achieved through goals, policy objectives and an overall strategy that will inform the implementation process.

3.2 What does society need to look like to deliver this vision?

There needs to be a shift in attitudes – both towards disabled people and by disabled people themselves

A significant barrier at the moment is negative attitudes towards disabled people, which can be transmitted either knowingly or unknowingly, directly or indirectly. These attitudes tend to cast disabled people as needing care or control,

or as lesser human beings who do not fit into ‘normal’ society.

In order to deliver the vision described in Section 3.1, these negative attitudes – which one report has labelled ‘disablism’⁵⁶ – need to be replaced by a recognition of disabled people as full citizens and as equals to non-disabled people.⁵⁷ The media has an important role to play in this process, for example by representing disabled people as citizens capable of leading interesting and fulfilling lives, and contributing to society.

There also needs to be a better understanding of disability and impairment in society, so that people understand what disability is, in particular the role of barriers in perpetuating exclusion. To address multiple sources of disadvantage, progress will also need to be made in attitudes on other diversity issues including gender, race, age and sexuality, which can be experienced by both disabled people and non-disabled people⁵⁸.

Box 3.2: The scope and nature of discriminatory attitudes

Negative attitudes towards disabled people can stem from a range of sources including ignorance, lack of experience, and fear. They can occur at the individual or collective level, either directly or indirectly. Personal discrimination includes avoiding

⁵⁶ Demos (2004) *Disablism: How to tackle the last prejudice*.

⁵⁷ See the Scope Time to get equal campaign (www.timetogetequal.org.uk).

⁵⁸ See Social Exclusion Unit (2004) “Breaking the Cycle: taking stock of progress and priorities for the future”.

interaction with an individual or giving an individual different treatment. Discrimination can also be collective, such as using derogatory terms about disability or portraying negative or inaccurate images of disabled people in the media. Collective discrimination can be institutional or cultural.

The following polling data indicates the current level and scope of discrimination.

- 21% of disabled respondents experienced harassment in public in relation to their impairment (DRC, 2003).
- In a Scottish survey of disabled people, almost half had experienced verbal abuse, intimidation and /or physical attacks because of their impairment. Almost a third of respondents were experiencing attacks at least once a month that were most likely to be from strangers and in public places such as the street and public transport (DRC and Capability Scotland, 2004).
- 49% of respondents with mental health conditions had been harassed or attacked, and 26% had been forced to move home because of harassment linked to their mental health condition (Read and Baker, 1996).

- 17% of disabled respondents said they had experienced actual discrimination in the workplace because of their disability (DWP Attitudes and Awareness, 2002).

Any shift in attitudes must also involve disabled people and their families. This group can have lower self-esteem and aspirations, often as a result of direct negative experiences of discrimination and barriers. They are also members of society, and are therefore exposed to wider societal attitudes and expectations articulated through the media and other forums. A change in attitudes towards disabled people will empower individuals and their families to take up opportunities and choices to improve their life chances, with the appropriate support.

Disabled people need to be integrated into society and their needs fully taken into account

Society has come a long way with respect to gender and ethnicity issues, although there is still much progress to be made. However, recognition of disability issues arguably lags behind in terms of the extent to which it is incorporated into the structures of business, government and wider society.

Box 3.3: The diversity agenda: disability, race and gender

As highlighted in Section 3.2, the wider diversity agenda seeks to address the disadvantage and discrimination faced by a range of groups, including discrimination on the grounds of race, ethnicity, gender, sexual orientation, age and religion. There is much common ground between these groups in terms of the nature and impacts of discrimination and exclusion. And disadvantage can be compounded by the multiple aspects of identity.

However, the basis of civil rights between groups is somewhat different. The Race Relations Act 1976 and the Sex Discrimination Act 1975 seek to make sure that different groups of people are treated equally in order to achieve equal outcomes. But, the Disability Discrimination Act 1995 requires employers and others to treat disabled people differently to reduce their barriers to participating in society and to achieve equality of outcomes for disabled and non-disabled people. This is equivalent to requiring positive treatment of disabled people in some contexts.

The Commission for Equality and Human Rights will bring together the current equality Commissions in a single body that will take responsibility for new laws on age, religion or belief and sexual

orientation, and for the first time provide institutional support for human rights.

For the vision in Section 3.1 to be achieved it will be necessary for disability issues to be incorporated as an integral component of the way in which all of society goes about its activity. The Disability Discrimination Bill public sector duty (Box 3.4) is intended to promote this process within the public sector.

Increasing the employment rate among disabled people will help promote social inclusion and should also reduce negative attitudes from others. For those who cannot realistically participate in the labour market, resources should be directed to enabling their inclusion in their local communities. The long-term aim is that disabled people participate in society on the same terms as non-disabled people. Mainstream policies and business should therefore be designed and implemented to take account of the needs of disabled people, alongside all other citizens. This will require widespread sign-up to the net benefits of 'reasonable adjustments' as set out in the DDA.

Box 3.4: The Public Sector Duty: promoting equality of opportunity for disabled people

The Disability Discrimination Bill will introduce a positive duty on the public sector to have due regard, when carrying out its functions, to the need to eliminate unlawful discrimination against, and harassment of disabled people, and to promote equality of opportunity for disabled people.

There are 'specific duties' under the duty to promote equality, including a requirement for a Disability Equality Scheme that sets out:

- how disabled people have been involved in drawing up the scheme;
- how the public authority will assess the impact of existing and proposed policies and activities on disabled people;
- the steps the public authority will take to improve outcomes for disabled people;
- the way the public authority will gather evidence on whether outcomes are improving for disabled people; and

- the way the public authority will use the evidence they have gathered.

The aim of the positive duty is for the public sector to become an exemplary employer; responsive to the needs of disabled people through its service delivery; and a driver for wider change through its relationships with contractors and its regulation of the private sector.

3.3 What are the rights and responsibilities of the different players?

The delivery of societal change will require action by: the wider community including disabled individuals; government; the wider public sector; employers; and providers of goods and services. Without clarity on the rights, roles and responsibilities needed to achieve the vision, different people or groups may duplicate effort, take conflicting action, or simply do nothing at all – and it will be disabled people themselves who lose out.

- The rights of all citizens, including disabled people, are a mixture of codified rights and publicly-defined and politically-contested values⁵⁹.
- Alongside rights, it is widely accepted that people also have

⁵⁹ In addition to the legislation described in Chapter 1, the Human Rights Act (1998) guarantees the right to life, right to liberty, to privacy, to freedom from degrading treatment, right to marry and found a family, and the right to education, subject to compatibility with primary legislation; and the Scottish Executive, Northern Ireland Assembly, Welsh Assembly Government and the Greater London Authority all have positive duties to promote equality.

responsibilities. These reflect specific obligations set out in law and also wider perceptions of what citizenship means and the values that underpin it. For example, when a citizen receives public funds through certain welfare payments, such as Job Seekers Allowance, it is widely accepted that the individual has a responsibility to take up opportunities for work or training⁶⁰. These responsibilities can be implicit – reflecting social norms – or explicit through, for example, conditions attached to benefits.

Common understandings of rights and responsibilities change over time and are contested in the public realm. This is demonstrated by current debates on whether citizens have a responsibility to maintain a healthy lifestyle. Individuals in particular roles – such as benefits claimants – can assume specific new responsibilities, based on a contractual-type relationship between individual and state. The ability to meet responsibilities may be affected by barriers, such as social barriers to taking up employment. So, for responsibilities of disabled people – for example – to be met, barriers will need to be tackled and support will need to be provided to disabled people in their roles as citizens, parents, employees and so on.

In the context of disability, different groups within society need to

recognise their own rights and responsibilities, so that progress can be made towards achieving the vision. The following list illustrates some rights and responsibilities of key groups.

- **Disabled people:** have largely the same rights and responsibilities as other citizens, with additional rights set out in the Disability Discrimination Act 1995 and SENDA 2001. Like other citizens, if a disabled person is in receipt of benefits or public services, they may have additional responsibilities, for example, to seek opportunities to take up employment. Disabled people, alongside other citizens, also have a responsibility to inform service and benefits providers of any relevant changes in their personal circumstances.
- **Employers:** have specific responsibilities including health and safety provisions for all their employees. Employers also have additional DDA responsibilities towards potential or current disabled employees. Some employers recognise a wider responsibility to employees and society through corporate social responsibility.
- **Service providers:** Health and social care agencies have statutory duties to meet additional needs. Providers of goods, services and facilities have responsibilities not to discriminate against disabled

⁶⁰Strategy Unit (2004) “Personal Responsibility and Changing Behaviour: the state of knowledge and its implications for public policy”.

people, including through making 'reasonable adjustments' to physical premises.

- **Government and the wider public sector:** Local authorities have a duty to promote economic, social and environmental well-being in their area. They also have a duty towards disabled people under Section 21 of the National Assistance Act 1948. Public bodies, under the Disability Discrimination Bill, are also likely to have a duty to promote the equality of disabled people.
- **Carers:** are supported through local authority powers to provide services for people with caring responsibilities. Many carers take on informal support of disabled people close to them, such as family members, neighbours and others.
- **Wider community:** has a widely recognised responsibility to treat others with dignity and respect.

3.4 What justifies government intervention to achieve these outcomes?

Disabling barriers reduce life chances, exclude disabled people and waste their talents and abilities

Disabling barriers – such as discrimination, the built environment, and policy design – have a damaging effect on life chances and lead to many disabled people living in poverty, social exclusion and with low educational

outcomes. The result is that many disabled people face social and economic marginalisation from society. These poor outcomes for disabled people create a high level of inequity.

This matters for disabled people themselves, as well as for carers and families. It also matters for society as a whole, because we lose the talent and contribution of disabled people. The exclusion of disabled people from mainstream society also means that they participate less in public life and institutions. This means fewer voices are being expressed and taken into account in the democratic process and in the creation of the values and norms that shape society.

Disabling barriers also impact on economic growth and productivity

With less than half of disabled people of working age in employment, there is significant wastage of disabled people's potential contribution to economic growth and productivity. The status quo seeks to compensate disabled people for impairment and disabling barriers, rather than supporting them to improve their quality of life. As detailed in Chapter 2, this not only costs the public purse in benefits spend, it also reduces the economic and social contribution of many disabled people who could be better supported to participate in the workplace, in their local communities and in society generally. Effective government action to improve the life chances

of disabled people should in many cases deliver net economic benefits, and result in more efficient use of public resources.

There are a number of reasons why the vision would not be achieved without government intervention

Disabling barriers, which prevent disabled people from being fully included in society, need to be actively addressed by government. Without action, existing behaviours, attitudes and structures will continue to marginalise disabled people. This should include government leading by example, demonstrating positive attitudes towards disabled people, and being a model employer.

At the same time, disabled people have additional needs which may require support. The type of support required can vary. For example, personal assistance or support to perform daily activities, advocacy to make informed decisions, adaptations to housing in order to live independently, interpreter or equipment to enable communication. The costs of meeting additional needs, particularly for those on lower incomes, would be prohibitive if borne by the individual alone. Government action reflects society's responsibility to make sure that all people are enabled to live with dignity and to participate in and contribute to their local communities.

Finally, government intervention can address market failures – such as discrimination against disabled people by employers and service providers because of a lack of information about their skills and abilities. These market failures would continue without state action and undermine efficiency and social goals.

3.5 What does government need to do to deliver on the vision?

To achieve the vision, government needs clear principles to inform all policymaking. These principles should feed into a strategy that is implemented through a coherent delivery process.

All three components – policy principles, strategy and delivery – should be consistent and self-reinforcing.

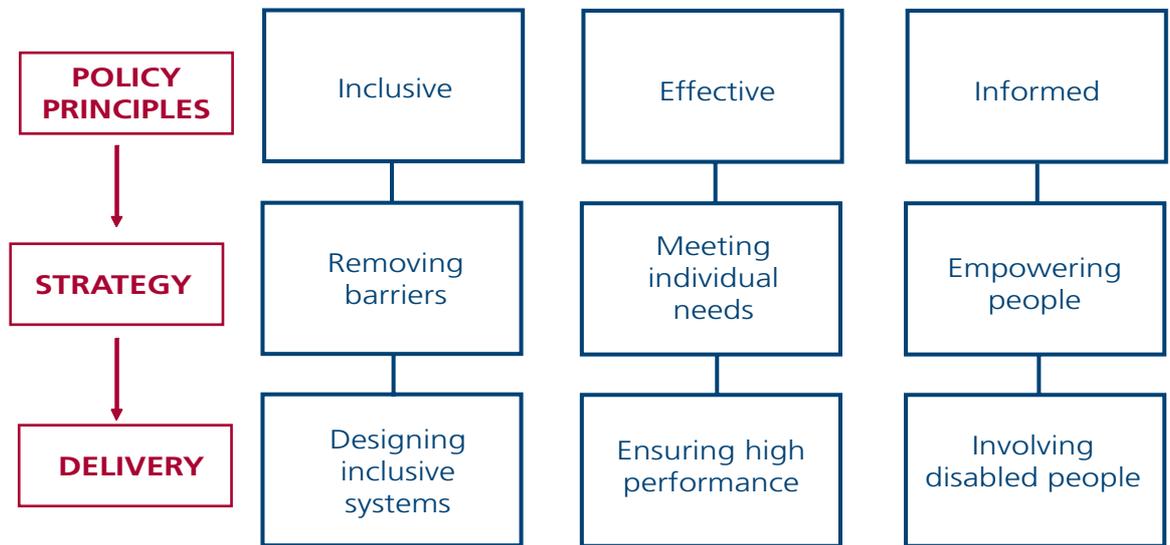
Policy design needs to be inclusive, effective and informed

To ensure that policy design is consistent with the overall vision and contributes directly to the achievement of the vision, policy should be based on the following three principles.

Inclusive

- Disabled people to be enabled to contribute to the life of their local communities and to society generally, supported by both specialist and mainstream policy. Disabled people's needs should be

Figure 3.2 Connections between the policy principles, strategy and delivery of the vision



actively incorporated early on within all mainstream policy design and delivery, alongside other citizens.

A soundly-based strategy will remove barriers, meet individual needs and empower disabled people

Effective

- Disabled people should receive individualised responses to their additional requirements, to a high standard, when they need them, for as long as they need them; so that they are empowered as consumers and citizens.

Each of the principles above is linked to a component of the strategy for long-term change. This strategy will inform the basis for government intervention in this area and will focus action on the most critical areas.

Informed

- Policy design and delivery should be informed by disabled people themselves, their experiences and preferences. Disabled people should be supported to make informed choices, through peer advice and advocacy.

Removing barriers: ensuring that disabling environments, attitudes and disproportionate social barriers are effectively removed. This will require:

- agreement on the barriers – in attitudes, policy, physical environment, and communication – and shared ownership of the solutions.

Box 3.5: Removing barriers in practice

Inclusive design of products, services and environments can mean that people of all abilities and ages are able to use them in their everyday lives. Examples include:

- accessibility audits of buildings to improve mobility for everyone from wheelchair users to mothers pushing prams; and
- a big-button phone selling as a mainstream product irrespective of visual impairment.

This process involves designers, manufacturers and service providers actively considering the widest possible audience for their products and services. It promotes an inclusive society by removing barriers through the design and production process⁶¹.

Meeting individual needs: providing financial and service-based support to meet additional individual needs where appropriate. This will require:

- assessment of need, identification of available resources, and personalised responses to need which enable choice and control.

Box 3.6: Meeting individual needs in practice

Additional needs arising from impairments – such as health provision, equipment, therapy services, and language support – should have personalised responses. This could mean personal assistance being provided at a time of day that enables a person to go to work, or health support through the Expert Patient model that creates mutual support between the patient, their peers with similar needs and specialist health support workers. These responses should be developed with the individual and provided in a way that enables choice and control, and promotes the principles of independence and inclusion.

Empowering people: empowerment by and of disabled people, with an ongoing opportunity to voice concerns and critical challenge. It will require:

- individual empowerment, raised expectations, democratic voice, meaningful choice and self-esteem – so that disabled people are able to take up opportunities to improve their life chances, and all stakeholders are expected to facilitate this outcome.

Empowerment of disabled people will be an important part of the new public sector duty on public authorities, through the process and outcomes of the Disability Equality Scheme.

⁶¹See www.inclusivedesign.org.uk for more information.

Box 3.7: Empowering people in practice

Disability organisations and disabled people should be involved early on in policy and service development on a systematic basis. Essex County Council has an Independent Advocacy Service staffed largely by disabled people. This body is involved in policy-making at the County Council, including devising a commissioning process that promotes equality of disabled people, and holds the Council to account on issues such as its target for employment of disabled people.

Those who work with disabled people and provide services should also be encouraged to support disabled people in ways that maximise their independence and participation in community life.

Effective delivery will be essential to securing improved outcomes

This strategy needs to be converted into a sound delivery process that ensures that the vision is achieved through tangible and specific actions. The delivery process will be coordinated by government but will need others to take it forward at the same time. This process is described in detail in Chapter 8. It has three main parts, which correspond to the principles and strategy above.

- Designing inclusive systems.
- Ensuring high performance.
- Empowering people.

Any plans for government intervention need to take full account of the possible costs of that intervention

Government intervention, in any area, can have a number of consequences that need to be anticipated through the regulatory impact process. Government needs to make sure that action it takes is beneficial and better than no intervention at all or leaving things as they are. The recommendations in this report have been subject to an initial assessment of regulatory impact. As the recommendations are taken forward through the implementation process, full Regulatory Impact Assessments will need to be developed by government departments. These will set out and assess the costs and benefits to different groups within society.

3.6 What wider issues will affect progress towards the vision?

Achieving the vision, goals and objectives set out above, through the principles, strategy and delivery channels, will involve tough decisions. There may be trade-offs between certain benefits and costs, or decisions to be made about the sequencing of action.

There needs to be an effective relationship between social care and health care

Additional needs associated with impairments mean that many disabled people require support from either or both the health care system and the social care system. However, these two systems are founded on very different notions. Health care is based on the principle of 'free at the point of use' (with income-related exceptions such as eye tests and prescriptions) whereas social care uses cost-sharing principles. This can lead to situations where care services which appear very similar to the individual can be administered on very different grounds. For example, a wheelchair could, in some circumstances, be argued to be a social care need rather than a health need, but is provided free by the health service; while help with personal care at home could in some circumstances be argued to be a health need, but is provided by social care.

In developing an effective support system based around individual needs, whether these are predominantly 'health' or 'social' in nature, this divide will need to be managed. Health Act flexibilities have already enabled better joint working in some localities and for some groups of people, but further work needs to be done. The forthcoming Green Paper on Adult Social Care may address some of these issues.

Importantly for children and for life-long learners, the relationship between social care and health care also needs to interface successfully with education. The follow-up to the Green Paper "Every Child Matters" is aiming to integrate health, social care and education services around the needs of children and their families to improve outcomes.

There is a balance to be struck between mainstreaming and specialist provision

As set out above, all policy delivery and design should take disabled people's needs into consideration, so that they are better able to access mainstream services. There will also be circumstances in which disabled people require additional support in order to access mainstream services; and where specialist support will be required in order for disabled children and adults to be involved in their local communities and in society generally. Specialist support may sometimes better promote the well-being of a disabled person. The aim of both mainstream policy and specialist provision should be that of social inclusion for disabled people of all ages.

There also needs to be a balance between national standards and local autonomy

There are difficult decisions to be made on the degree to which national standards are set and the degree of freedom which local bodies have to meet local priorities.

In the context of disability this means that once the vision and overarching goals are agreed, there will need to be decisions about the best way of achieving them. This may mean some combination between enforceable national standards coupled with clear signalling of outcomes, so that local authorities can make local decisions that best reflect local needs, while working towards the same goals and vision.

Government has agreed that the number of targets it sets should fall, to ensure a focus on a few clear national priorities and to increase flexibility for those at the front line to respond to local priorities and circumstances. For some priorities of national importance, minimum standards should be set and where poor performance is identified, targeted inspection will help authorities identify key areas for improvement. For those priorities that are local, it must be local authorities themselves to decide on the most appropriate targets and means of achieving those targets.

Box 3.8: Local Public Service Agreements

Local Public Service Agreements (LPSAs) are being used by local authorities to drive through improved outcomes at the local level, through joint working between agencies to agreed outcomes. Local authorities who successfully meet their LPSAs are

rewarded through a Performance Reward Grant from central government. Here are some examples of innovative LPSAs that are linked to disability issues.

Several local authorities – including Cumbria County Council, Luton Borough Council, North Somerset Council and Poole Borough Council – have LPSAs on improving the employment rate of disabled people.

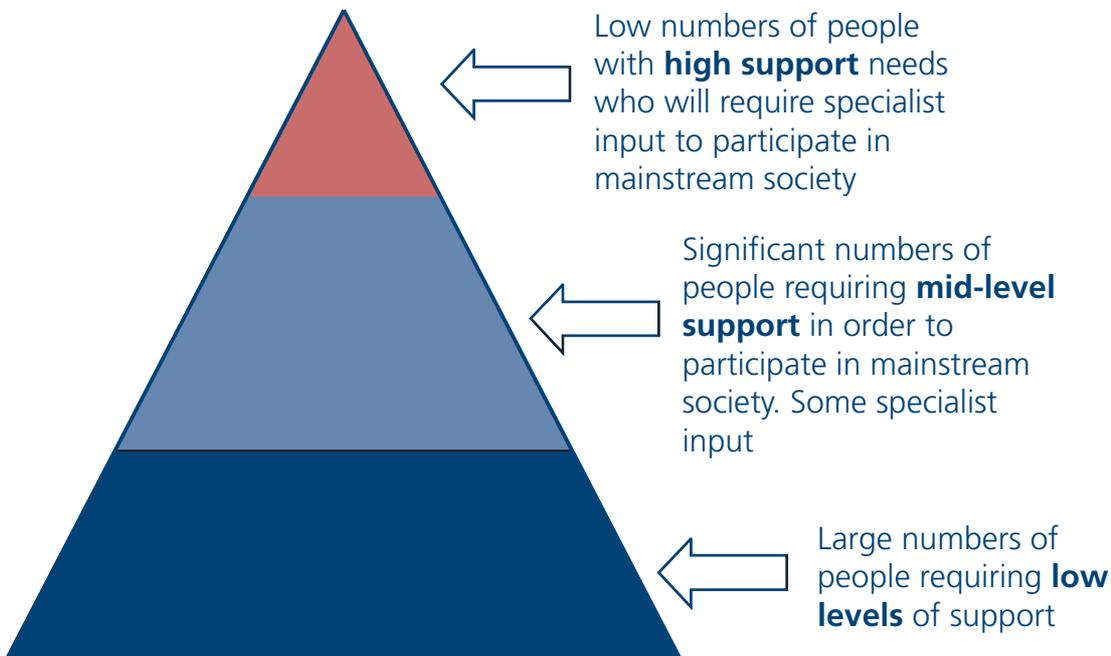
Shropshire County Council has an LPSA to increase the choice and control and improve the general quality of life for people with learning disabilities.

Cheshire County Council has an LPSA to boost independence, choice and control by increasing the take up of direct payments by adults, older people, disabled children and their carers.

Government resources will need to be targeted effectively

Some of the policy objectives can be achieved within existing budgets, including through efficiency savings. Other policy objectives may require pump-priming resources to enable service deliverers and others to transform their policy delivery to be consistent with the goals. This could be on an ‘invest-to-save’ basis – so that spend in one area generates savings in another area and/or over the longer term – or indeed to get better outcomes from existing spend.

Figure 3.3 Representation of different levels of needs in the population



There are other decisions on spending including the balance between spend at different points in the life cycle and between different goals in the vision. Spend can also be allocated between different levels of need. The diagram above is a representation of the spread of needs within the population of disabled people.

This diagram is, necessarily, simplified. In reality, people may have specialist support needs in certain environments but none in

other places. Many disabled people need a varying combination of both mainstream and specialist provision. In addition, people with fluctuating or deteriorating conditions may move between the population groups over time.

Depending on the overall resources available and other priorities for government spend, these decisions will need to be taken based on the best evidence available and in a transparent manner.

Chapter 4: Independent living

Summary

Historically, disabled people have been treated as being dependent and in need of 'care', rather than being recognised as full citizens. This has meant that:

- responses to needs have often created dependency, rather than promoting independence and extending opportunity; and
- disabled people have been expected to fit into services, rather than services being personalised to respond to individual need.

A new approach to supporting disabled people is now needed, in line with the Government's new vision for adult social care. This should focus on the promotion of independent living. Independent living is not just about being able to live in your own home – though that is often part of it for many disabled people. Rather, independent living is about providing disabled people with choice, empowerment and freedom.

The new approach should allocate available resources according to individual needs, in the form of individualised budgets made transparent to the disabled person. Individuals should be able to choose whether they take this in cash or services – either way, the budget should be used to secure the appropriate type of support for the individual.

This new approach would require radical changes to the way in which budgets are organised and services are delivered. The options for a new system to deliver this approach should be piloted – and disabled people themselves will need to be at the heart of these pilots.

In parallel, action should be taken in a number of other areas.

- Building capacity amongst disabled people and their organisations so that they are empowered to influence policy and service delivery.
- Ensuring that disabled people are included in mainstream policy and services.
- Addressing the barriers disabled people experience in accessing housing and transport.

Section 4.1 of this chapter outlines what is meant by the term 'independent living' and summarises the current situation. The key barriers are detailed in Section 4.2 and evidence of what works in tackling these barriers is presented in Section 4.3. The recommendations for change are described in Section 4.4. The exact nature of the new system will need to be determined through the piloting process. It will also need to take account, in parallel, of issues that emerge from the consultation on the Green Paper on Adult Social Care.

4.1 What do we mean by "independent living"?

The Disability Rights Commission has defined independent living as referring "to all disabled people having the same choice, control and freedom as any other citizen – at home, at work, and as members of the community. This does not necessarily mean disabled people 'doing everything for themselves', but it does mean that any practical assistance people need should be based on their own choices and aspirations⁶²".

Disabled people stress that, just because someone might need assistance to go about their daily life, this does not mean they have to be 'dependent'. Independence comes from having choice and being

empowered regarding the assistance needed. Without this choice and empowerment, disabled people are unable to fulfil their roles and responsibilities as citizens.

The philosophy accords with the Government's new vision for adult social care and the debate that has underpinned the consultation leading to the forthcoming Green Paper.

Independent living is not just about having choice and empowerment in personal care. For Deaf people and those with communication impairments, independent living is about interpreter and/or communication support. For people with mental health support needs, advocacy is "a vital component of independent living. Mental health service users need advocacy support, just as people with serious physical impairments need personal assistance⁶³". People with learning disabilities stress self-advocacy, which for them is about having support to 'speak up for ourselves', something too often denied to this group of disabled people in particular⁶⁴.

Indeed, there are many aspects of people's lives where the existence or absence of disabling barriers will determine whether they can be active citizens. Housing suitable for their needs, transport, assistance

⁶²Disability Rights Commission (2002) *Policy Statement on Social care and Independent Living*, DRC.

⁶³Disability Rights Commission (2003) *Coming Together: Mental health service users and disability rights*, DRC.

⁶⁴Ward, L (1999) *Innovations in Advocacy and Empowerment*, Lisieux Hall Publications.

and equipment to enable mobility are just two important areas. So too is the provision of health care: a wide range of health services can make all the difference to whether someone can live independently, work, be a parent and participate in their local community.

Independent living is therefore an important part of enabling disabled people to fulfil the roles and responsibilities of citizenship. Its importance spans the full range of life experiences faced by disabled people, from early years and transition to adulthood through to adult life and employment, extending into old age. While this chapter focuses on the core elements needed to support independent living for disabled people covered by this report, the principles – and some of the recommendations – are equally relevant across chapters 5–7.

Some progress has been made in supporting independent living

While progress in recent years means that more disabled people are living in their own homes and are participating in society, there is still a long way to go. Moreover, there are aspects of government policy which (unintentionally) create barriers to disabled people's vision of independent living.

Chapter 5 sets out the barriers faced by disabled children from an early age, while Chapter 6 summarises evidence of the disadvantages

facing young disabled people as they make the transition into adulthood. These barriers can have long-term consequences, leading to the higher rates of unemployment and poverty detailed in Chapter 7. But there are wider consequences too. There is now considerable evidence that people with physical and/or sensory impairments, learning disabilities, or mental health support needs are less likely than their peers to experience the 'normal activities' which are generally considered to be part of an experience of social inclusion. These 'normal activities' are "to have a reasonable living standard, to possess a degree of security, to be engaged in an activity which is valued by others, to have some decision-making power, and to be able to draw support from immediate family, friends and a wider community⁶⁵".

Box 4.1: The current policy context for independent living

A number of current and forthcoming policy initiatives form part of the context of this chapter.

- The national learning disability strategy, Valuing People.
- National Service Framework on Long Term Conditions.
- National Service Framework on Mental Health.
- National Service Framework for Children, Young People and Maternity Services.

⁶⁵Burchardt, Tania, Le Grand, Julian and Piachaud, David (1999) 'Social exclusion in Britain 1991–1995' *Social Policy and Administration*, Vol 33, No 3, pp 227-244.

- Direct Payments Implementation programme.
- NHS programme for Chronic Disease Management.
- The Expert Patients Programme.
- Integrated Community Equipment Services.
- Supporting People programme.
- The public sector duty to be introduced in the forthcoming Disability Discrimination Bill.
- Adult Social Care Strategy and forthcoming Green Paper.
- The Mental Capacity Bill

The Department of Health intends later this year to carry out a major consultation on the future of adult social care. Many of the themes and issues raised in this chapter are central to this consultation. The emphasis will be on using resources in ways which personalise responses to needs, maximise choice and control, and promote independence through earlier interventions. Services need to be seamless, with partner agencies and professionals working to improve coordination and accessibility. We expect that the Department of Health's response to its consultation will deal with many of the issues that are covered here. The outcome of the consultation should set a new direction for the delivery of social care, including to disabled people.

4.2 What are the key barriers?

Two main barriers are evident across all aspects of disabled people's lives – in where they live, their personal relationships, their opportunities for education, training and employment; access to healthcare; access to leisure activities; and participation in the life of their local community and in wider society.

- The support which society makes available to people with a range of different impairments is generally not fitted to the person. Instead, disabled people are expected to fit into services. Support is organised and delivered according to different policy, professional and service boundaries, resulting in unnecessary bureaucracy, a fragmentation of disabled people's lives and often a failure to meet their needs adequately.
- Policies and practice do not pay enough attention to enabling disabled people to be active citizens, or to supporting disabled people to help themselves. There is instead a focus on incapacity, inability or risk associated with impairment or mental health needs. Responses to needs are often more likely to create dependency than enable people to participate in their local communities, fulfil their family responsibilities or be economically independent.

Within these broad categories, some specific problems can be identified.

Inappropriate assumptions underpin the legislative framework for support

The Strategy Unit Expert Group on Independent Living stated that independent living initiatives are constrained by a welfare system which assumes dependency.

The National Assistance Act 1948 underpins later community care legislation and provides the legal definition of a disabled person as far as community care policy is concerned. This is someone who is “blind, deaf or dumb, or who suffers from mental disorder of any description and other persons who are substantially and permanently handicapped by illness, injury or congenital deformity.” (National Assistance Act 1948, Section 29(1)). This definition is out of date, offensive and does not provide a useful starting point for enabling disabled people to fulfil their roles as citizens. Disabled people themselves have insisted that it is not impairment or illness in itself that determines their life chances but the social, economic and environmental barriers they face.

One of the most significant barriers to enabling disabled people to be full citizens is the culture of care and dependency within health and social care structures. Associated with this ‘culture of care’ is a failure to see expenditure on independent living as a form of social and economic investment. Instead of meeting disabled people’s additional

requirements to enable them to improve their life chances, resources are used in ways that maintain and create dependency. This results in higher than necessary expenditure on social security benefits; segregated services; and lost revenue from taxes paid by disabled people and family members who provide ‘informal care’⁶⁶.

However, the current system of allocating public resources does not make transparent the costs of failing to enable disabled people to achieve independent living. Decisions about health and social care and other public expenditure are not always informed by a cost-benefit analysis which takes the wider costs of dependency into account.

Support is often characterised by fragmented and silo-based approaches

The dividing line between health, social care, housing, education, employment and other public policy areas, at both national and local levels, makes it difficult to take a comprehensive and cost effective approach to meeting disabled people’s needs.

There are many examples where expenditure by one government or local authority department means less expenditure for another department, yet this is not recognised. This results in insufficient incentive to spend money from one budget in order to decrease expenditure from another

⁶⁶Zarb, G. (1998) *What price independence?* Unpublished paper available from Disability Rights Commission.

and can result in not only a poorer quality of life for disabled people, but an inefficient use of public resources.

Box 4.2: Inadequate responses to need can create unnecessary dependency and diminish disabled people's life chances

The British Polio Fellowship told the Strategy Unit that inadequacies in orthotics services can lead to increased reliance on other public services.

Mr. E had been prevented from working because he has had on-going problems getting properly fitting orthopaedic boots from the orthotic services.

Miss M had been waiting 10 months for orthopaedic shoes and a calliper and was not able to leave her home during this time. She was therefore unable to attend the self-management course (part of the Expert Patient Programme) and has been having increasing difficulty managing her condition.

These experiences can lead to increased dependency on health and social care services and undermine people's ability to work and to be active citizens⁶⁷.

A fragmented approach to disabled people's needs also means that a

failure of one public body to meet a particular need can create costs for another. For example, in most parts of the country there is a higher demand for adaptations than can be met from existing budget allocations for disabled facilities grants. Because the Disabled Facilities Grant (DFG) is mandatory, this excess demand can mean long waiting lists, resulting in:

- accidents and hospitalisation during the time that people wait for adaptations (particularly those concerning access to toilets and washing facilities); and
- people becoming dependent on personal care, and finding it difficult to manage without this assistance even once the adaptation or equipment has been provided⁶⁸.

At the same time, there is evidence that providing appropriate equipment and adaptations increases independence, reduces the need for personal assistance and prevents or reduces health problems. In one study, three out of four people said housing adaptations had helped their health, while a third of those who received minor aids and adaptations (costing less than £500) reported that they needed less help from others⁶⁹. But savings to the NHS and to social care budgets are not part of decisions – at central or local level – about expenditure on equipment and adaptations.

⁶⁷Strategy Unit consultation.

⁶⁸Heywood, F. (2001) *Money well spent: The effectiveness and value of housing adaptations*, The Policy Press.

⁶⁹Heywood (2001).

Improving the suitability of new-build and renovated homes for disabled people would also help reduce future public expenditure on housing adaptations, equipment and care services. Adopting Lifetime Homes Standards would save, on average, £1,100 per dwelling on the cost of major adaptations while the average cost of building a three bedroom, five person house to Lifetime Homes Standards was calculated to cost an additional £100 to £300 per dwelling (in 1997 prices). This was calculated to be a total saving of £39million per year on major adaptations⁷⁰. Further savings would also be made in terms of expenditure on minor adaptations and equipment, care services, hospital stays, and temporary residential care. Lifetime Homes Standards apply to all age groups, including children and elderly people, so the potential savings would be significant.

There is a fragmentation of disabled people's needs across a range of different systems

Box 4.3: Fragmentation can result in needs not being met and a duplication of resources spent on assessment, delivery, and monitoring

Kelly is a 24-year-old wheelchair user, who has just moved into her first flat and started her first job. In the last year she has had to deal with six different systems in order to meet her needs. The wheelchair

service assessed her for a new wheelchair; Access to Work assessed her for a desk and computer equipment; social services assessed her need for a disabled facilities grant and minor adaptations to her flat; the housing department carried out a financial assessment to see if she should make a financial contribution towards the cost of adaptations; another section of social services assessed her for personal assistance costs up to £265 a week; the Independent Living Fund assessed her for personal assistance costs over and above this amount⁷¹.

The Health Act 1999 made it possible for local health and social services to work together, by pooling budgets, integrating services, or designating one agency to be the lead commissioner. Disabled people's needs, however, are not confined to health and social services. Moreover, there are often disputes between health, social services and other organisations as to who is responsible for meeting a particular need. For example, someone in employment who requires an electric wheelchair may still face arguments between the local Wheelchair Service and Access to Work as to who is responsible for providing it; a person with learning disabilities whose Person Centred Plan says they need to go to a course at the local College still faces

⁷⁰Cobbold, C. (1997) *A cost benefit analysis of Lifetime Homes*, Joseph Rowntree Foundation.

⁷¹Personal communication as part of Strategy Unit consultation.

difficulties with identifying who is responsible for funding the transport to get there.

Within both health and social care services there is a further fragmentation of people's needs. "Health and social care services were designed to meet single rather than multiple needs: each individual branch... has grown up with a fixed idea of what constitutes their 'core business'. Thus there is an inbuilt inflexibility about meeting the full range of people's needs⁷²."

For example, people with physical impairments and mental health support experience a fragmenting of their needs across physical disability and mental health services. There is often a failure of physical disability services to take account of mental health needs, and vice versa, and a lack of communication between the two services⁷³.

The failure of services to meet the needs of people with learning disabilities and people who are Deaf or hearing impaired, who also have mental health support needs, has also been well documented^{74,75}.

A failure to address people's needs in a holistic manner can result in some needs not being met.

This can mean that disabled people are unable to fulfil their full responsibilities as family members or as citizens. For example, a disabled parent needing help with both personal care and with the practical tasks of parenting may qualify for help with the former from the Independent Living Fund (ILF), but the Fund's Trust Deed precludes assistance with the latter. This means, as one parent put it, "They will fund the physical assistance I need to do the shopping, but they won't fund the physical assistance I need to pick the children up from school so my husband is faced with the decision of whether he should pack up work⁷⁶."

It is often inadequate responses to need that lead to a poor quality of life and unequal opportunities, rather than impairment in itself

The Independent Living movement has stressed that it is not impairment or illness that inevitably create dependency and lead to a poor quality of life. In fact, a poor quality of life is commonly created by:

- A failure to adequately meet needs relating to impairment.

⁷² Rankin, J. and Regan, S. (2003) Meeting Complex Needs: The future of social care, IPPR, p.12.

⁷³ Morris, J. (2004) "One town for my body, another for my mind": Services for people with physical impairments and mental health support needs, Joseph Rowntree Foundation/York Publishing Services.

⁷⁴ Foundation for People with Learning Disabilities (2002) Count Us In: The report of the Committee of Inquiry into meeting the mental health needs of young people with learning disabilities, Mental Health Foundation; Department of Health (2002) A Sign of the Times: Modernising mental health services for people who are deaf, Department of Health.

⁷⁵ The issues faced by those with complex needs are discussed in Annex F to this report.

⁷⁶ SU Consultation.

For example, we know that in many parts of the country people with head injuries do not receive adequate rehabilitation services⁷⁷. An audit of services to people with epilepsy found that 54% of adults and 77% of children had inadequate care⁷⁸.

- Disabling barriers can make worse or create impairment or illness. For example, there is evidence that people with learning disabilities experience unequal access to primary health care⁷⁹. Many people with learning disabilities are, as one professional put it, 'not well enough to lead ordinary lives'⁸⁰. This is not because of their impairment but because of the disabling barrier of inadequate access to primary health care.
- Services provided in response to the need for assistance can be disabling in themselves. For example, personal assistance to get up in the mornings may not be reliably available at the time someone needs it in order to go out to work. This may lead to the person losing their job (or not being able to seek employment). Unemployment in itself can in turn

have a detrimental effect on mental and physical health.

Assessments tend to be about services rather than needs

People are often expected to fit into services, rather than services enabling them to be active citizens.

"When the social worker came to see me she said she would assess me for whether I would qualify for direct payments or home care services. Actually what I wanted was to go to college to do an IT course so I could get a job. And I need help to do that"⁸¹.

One of the barriers to implementing direct payments has been that care managers have found it difficult to make the shift from assessing whether someone is eligible for a particular service to assessing what their needs are⁸².

While there have been improvements in recent years, it is still too often the case that:

- services are run on a 9am to 5pm basis, making it difficult to combine for example, using mental health services with full-time employment⁸³;

⁷⁷ House of Commons (2001), *Head Injury: Rehabilitation*, Third Report from the Health Committee, Session 2000-01.

⁷⁸ National Institute for Clinical Excellence (2002) *National Clinical Audit of Epilepsy-related Deaths*, National Institute for Clinical Excellence.

⁷⁹ Valuing People Support Team, *Key Highlights of Research Evidence on the Health of People with Learning Disabilities*, www.valuingpeople.gov.uk/documents/HealthKeyHighlights.pdf. Accessed 25.08.2004.

⁸⁰ Morris, J. (1999) *Hurtling into a Void: Transition to adulthood for young disabled people with "complex health and support needs"*. Pavilion Publishing.

⁸¹ SU Consultation.

⁸² Commission for Social Care Improvement (2004) *Direct payments: what are the barriers?* CSCI.

⁸³ Social Exclusion Unit (2004) *Mental Health and Social Exclusion*, ODPM.

- support is only available in specified settings, such as day centres, rather than to access a local college or other community facilities⁸⁴; and
- support at home is delivered in ways which make it easier for the service provider rather than in ways which fit in with the service user's life⁸⁵.

While direct payments and ILF grants can enable people to employ their own support workers, thus giving them more flexibility, not everyone wants to take on the responsibility for employing people. Moreover, in areas (both geographical and type of need) where it is difficult to recruit suitable workers, it is not empowering merely to pass on such difficulties to the disabled person to tackle⁸⁶.

People with significant cognitive and/or communication impairments are particularly at risk of being denied choice and control in their lives

Research in the field of learning disabilities, in both the United Kingdom and in the United States, has illustrated how a failure to provide a personalised response to

individual need can create additional needs and therefore additional demands on services⁸⁷.

Box 4.4: A failure to provide personalised responses to need can create additional needs which are hard and costly to meet

“David’s early years involved moving between special schools until he ended up at a residential school for children with autism. By the time he reached his 13th birthday he was living in a large hospital having been excluded from the special school system. After a few years living in a locked ward he was back with his family for short periods during the week and receiving a complicated cocktail of community and institutional services. During the week he would spend one night in hospital and one at a respite hostel where there were two staff on duty just for him. At the weekends support staff would come and work from the family home. During this time, David had built up a reputation. Words used to describe David were – ‘difficult to spend time with, destructive, without speech, aggressive, likely to hit out, a fast runner, autistic, hyperactive, a drain on the family,

⁸⁴Fyson, R. and Ward, L. (2004) Making Valuing People Work: Strategies for Change, The Policy Press.

⁸⁵Cunningham, S. 2000. Disability, Oppression and Public Policy, Independent Living (Keighley).

⁸⁶This was a point made to us by our Independent Living Expert Group and also by a group of parents of disabled children, brought together to consult with us by aMaze in Brighton.

⁸⁷Edge, J. (2001) Who’s in Control? Decision-making by people with learning difficulties who have high support needs, Values into Action.

ting to be with, an unknown quantity, mischievous, needs two staff with him when out, needs one-to-one when in⁸⁸.”

Some people have to move into residential care, against their wishes, because appropriate housing and support is not available

Some disabled people move into residential care against their wishes because services are too inflexible. This can also result from resources being tied up in existing residential provision. In one local authority area, for example, only 4% of learning disability revenue funding supports people with learning difficulties living in their own home. The other 96% pays for people to live in residential care services, with 60% of this allocated to large residential services⁸⁹.

The numbers of those with learning disabilities or mental health support needs who are placed in residential care increased by 20% and 40% respectively between 1997 and 2002. The numbers of people with physical and/or sensory impairments in residential care, having initially fallen, are now increasing.

Some of the increase in the numbers of people with learning disabilities in local authority funded residential care is related to the closure of long-stay hospitals. But a survey of services for people with learning disabilities, found that, although local health and social services agencies subscribed to ‘principles of social inclusion, citizenship and ordinary community living’, half of the authorities surveyed also expected to increase the number of placements in residential homes⁹¹.

Table 4.1: Local authority supported residents in staffed residential and nursing care at 31 March (1997–2002)⁹⁰

People aged under 65	1997	1998	1999	2000	2001	2002
Physically/sensorily disabled adults	10,356	8,734	9,094	9,690	9,498	9,755
People with mental health problems	7,965	9,277	10,208	10,560	10,995	11,275
People with learning disabilities	25,446	26,029	27,799	29,495	29,705	30,345

⁸⁸Sanderson H. Kennedy, J, Ritchie, P. with Goodwin, G. (1997) *People, Plans and Possibilities: Exploring Person Centre Planning*, SHS Ltd.

⁸⁹South Downs Housing Association (2002) *A place to live: Promoting choice and diversity for people with learning difficulties in Horsham and Mid Sussex*, South Downs Housing Association. www.doh.gov.uk/vpst/documents/lgpsingl.pdf

⁹⁰National Statistics/Department of Health (2003) *Health and Personal Social Services Statistics*, National Statistics.

⁹¹Department of Health (1999) *Facing the Facts: Services for people with learning disabilities. A policy impact study of social care and health services*, Department of Health.

There is also evidence of an increase in institutional care within the private sector for people who have both learning disabilities and mental health needs: such placements can cost local PCTs between £180,000 to £230,000 per person per year⁹².

The way in which the ILF operates also creates financial pressures towards residential provision. People whose total weekly support costs are over £715 per week are not eligible for an ILF grant. In these circumstances, instead of the local authority paying £295 per week and the ILF paying costs over and above this, the local authority would have to fund the entire cost of supporting them to live at home. Some people are forced into residential care as a direct result of the cost ceilings imposed both by the ILF and by social services departments⁹³.

Once people are placed in residential care they often have little or no further contact with the funding authority, particularly if they are placed out of the local authority area. Many people have a very low quality of life and some experience serious abuse⁹⁴. A disabled person living in residential care faces significant financial disincentives to seeking paid employment as they would only be able to keep £20 per week

of their earned income before it has to be used to pay for the residential home fees⁹⁵. In contrast, for someone living in their own home, earned income is not taken into account in the charging policy for community care services, direct payments or ILF grants.

Disabled people face a number of barriers to accessing suitable housing

This chapter has already mentioned that there is insufficient recognition of the role of housing repair, improvement and adaptations in the policy objectives of keeping people out of residential care and preventing hospital admissions and delayed hospital discharge. Despite the valuable assistance that Home Improvement Agencies provide to help disabled people adapt and repair their homes, some features of the DFG system create significant barriers.

While the DFG is mandatory, the resources available are cash-limited. Waiting lists and lengthy administration procedures are used to allocate scarce resources.

The DFG is subject to a means test that does not take into account outgoings such as mortgage repayments or expenditure on

⁹²Brindle, D. (2004) 'Private care for learning disabled people is a return to Victorian values', *The Guardian*, 04.08.2004.

⁹³Kestenbaum, A. (1999) *What price independence? Independent living and people with high support needs*, The Policy Press.

⁹⁴Pring, J. (2004) 'The frequency and potential consequences of the failure to visit learning-disabled adults in out of area placements' *Learning Disability Review* Vol 9, Issue 2, pp.35-42.

⁹⁵While the numbers of disabled people living in residential homes who would be able to work are small, the Strategy Unit did receive evidence that there are some in this situation.

children. This can create particular difficulties for younger households, such as a young couple where one person develops Multiple Sclerosis. Charging policies for community care services disregard earned income in order 'to avoid creating disincentives to work'⁹⁶.

Unfortunately, the DFG means test can then negate this policy aim as it does not disregard earned income.

There is an upper limit on the DFG. If adaptations cost more than this, it may well be that it would be better for a household to move – but there is no equivalent assistance in order to do this. There is evidence that sometimes adaptations are carried out which, while fitting within the cost limits, do not adequately meet the need and are therefore a poor use of public resources⁹⁷.

Box 4.5: Delays in processing applications for disabled facilities grants can have a considerable impact on disabled people's opportunities

Jane became paralysed as a result of a spinal operation. After five months in hospital she was ready to return home and go back to work. However, her application for a disabled facilities grant to adapt her flat to enable her to go home was subject to lengthy delays. She was also required to make a contribution to the costs of the

adaptations which she could only do by extending her mortgage. The delay in returning home meant her job was under threat, yet without her job she would not be able to afford the higher mortgage.

Adapted and purpose-built accessible housing is sometimes lost to the stock of accessible housing because social housing landlords often do not keep a record of such properties. When these properties come to be re-let therefore they are not always allocated to people who require the adaptations. Some local authorities run Disability Housing Registers (which match disabled households to suitable properties in the social housing sector) but – even though there is some evidence that they work – only a minority do so. One local authority estimated that savings of £850,000 (on adaptations and delayed hospital discharge) have been made over a two year period as a result of its Disability Housing Register⁹⁸. Experience within the owner occupied or privately rented sector is even more limited though growing. For example, there is a privately-run website (www.accessible-property.org.uk) but this is very new and it is unclear whether it is viable.

⁹⁶Department of Health (2003) Fairer Charging Policies for Home Care and other non-residential Social Services.

⁹⁷Heywood, F. (2001) Money well spent: The effectiveness and value of housing adaptations, The Policy Press.

⁹⁸HODIS (2004) A Perfect Match: Good Practice Guide to Disability Housing Registers, HODIS.

People who are living in residential care and who want to live independently often have difficulty accessing social housing as they are considered to be adequately housed and do not meet the allocation criteria for social housing⁹⁹. This is also a common experience of young disabled adults who want to leave the parental home, particularly because the private rented sector – the main source of housing for young non-disabled people – contains little that is suitable for disabled people¹⁰⁰.

Disabled people experience barriers in the context of transport

Transport is an important component of independent living but disabled people experience a number of barriers. Low incomes are one barrier, but this is then compounded by the additional transport needs of many disabled people.

The barriers faced by disabled people are not just the obvious physical ones relating to inaccessible public transport. Disabled people with whom this project consulted drew attention to a number of different issues.

- Getting to a destination can be jeopardised by just one barrier in the whole journey. For example, a pavement may have appropriate

texture changes for someone with a visual impairment but the bus may not have announcements about destinations.

- Negative attitudes of transport providers, and other members of the public, can make a journey impossible.
- The information that disabled people need in order to make a journey is not always available (for example which buses are accessible); moreover transport information to the general public is not always available in accessible formats.
- Transport needs are often not covered in social care assessments.

Policies and services that do not specifically target disabled people have tended not to address their needs or enable them to access services

Much of government policy is aimed at enabling people to play their role as active citizens – whether in terms of fulfilling their family responsibilities or participating in their local communities and the wider society. However, disabled people, having been treated as in need of 'care', are often overlooked and their roles and responsibilities as citizens unrecognised. This means, for example, that disabled adults are rarely thought of as also being

⁹⁹ Smith, Angela (1998) *I'm used to it now ... Disabled women in residential care*, Greater London Association of Disabled People; National Centre for Independent Living (2000) *Routes Out: Report of a Joint Conference*, National Centre for Independent Living.

¹⁰⁰ Esmond, D. and Stewart, J. (1996) *Scope for fair housing: A literature of housing with support for younger disabled people*, Scope; Kestenbaum, A. (1996) *Independent Living: A review.*, Joseph Rowntree Foundation.

parents¹⁰¹. Yet recognising the particular needs and circumstances of disabled parents will be vital to the achievement of policy objectives of increasing employment rates and tackling child poverty: only 30% of disabled lone parents are in paid employment compared to 55% of non-disabled lone parents¹⁰²; a quarter of children living in poverty have long-term sick or disabled parents¹⁰³.

Another example is Neighbourhood Renewal policies, where the long-term goals – a reduction in unemployment and crime, an improvement in health, skill levels, housing and the physical environment – have particular relevance to disabled people. Disabled people are also over-represented in deprived areas and it is therefore unlikely that PSA targets will be achieved without addressing their circumstances and needs. Yet there is some evidence that this has not happened as effectively as it should within the National Strategy for Neighbourhood Renewal and associated initiatives¹⁰⁴.

There are other services used by the general public (leisure services and libraries, adult education, transport, etc) which are not as accessible as

they should be to disabled people. While the Disability Discrimination Act has addressed some barriers, there is yet a need for more positive action to open up such 'universal' services to disabled citizens. Sometimes it is attitudinal barriers which get in the way, other times services need to take what they have to offer to where people are.

Box 4.6: Local services could play an increased role in enabling community participation

The SU expert group on mental health and independent living said that being part of neighbourhood and community networks is very important, but that these are difficult to sustain when someone experiences long-term mental health problems. Many long-term users of services have very little contact with anyone outside health and social services. Local services such as adult education, library and leisure services could play an important role in enabling community participation.

¹⁰¹ Wates, M. (2003) *It shouldn't be down to luck*, Disabled Parents Network; Morris, J. (2003) *The Right Support: Report of the Task Force on supporting disabled adults in their parenting role*, Joseph Rowntree Foundation.

¹⁰² Stickland, H. (2003) *Disabled Parents and Employment: Background paper for the HMT/DWP Seminar November 2003*.

¹⁰³ Gordon, D. et al (2000) *Poverty and Social Exclusion in Britain*, Joseph Rowntree Foundation.

¹⁰⁴ Edwards, C. (2001) 'Inclusion in Regeneration: A place for disabled people?' *Urban Studies*, Vol. 38 No 2, pp.267-286.

4.3 What is the evidence of what works?

Involvement of disabled people and their organisations improves the development and implementation of policy, and the delivery of services

The most successful public policy in the area of social care in recent years has been Direct Payments. This policy initiative resulted from disabled people (most with high levels of support needs and many of them in residential or nursing homes) demonstrating that cash payments were both an effective way of meeting their needs and an efficient use of public resources¹⁰⁵. Over time, disabled people and their organisations worked with researchers to prove that Direct Payments were efficient¹⁰⁶ and successfully campaigned for the Community Care (Direct Payments) Act of 1996.

Over a similar timescale, the ILF (created in 1988) proved a very popular and effective method of delivering support to some people with the highest levels of personal assistance needs¹⁰⁷. Disabled people set up personal assistance support schemes to provide support to people to use Direct Payments and ILF grants most effectively. The value

of such services is recognised in government guidance on the implementation of Direct Payments and in the administration of the Direct Payments Development Fund.

Box 4.7: Centres for Independent Living are grassroots organisations run and controlled by disabled people

Their aims are to assist disabled people take control over their lives and achieve full participation in society. There are currently 22 fully constituted CILs with another 15 local disability organisations either providing a similar role or working towards becoming a CIL. For most CILs their main activity, and source of income, is running support schemes to enable disabled people to use Direct Payments. Such schemes may involve:

- advice and information;
- advocacy and peer support;
- assistance with recruiting and employing Personal Assistants (PAs);
- a payroll service;
- a register of PAs; and
- training of PAs.

¹⁰⁵ Hampshire Centre for Independent Living (1986) One Step On: Consumer-directed housing and care for disabled people – the experience of three people, HCIL Publications; Campbell, J. and Oliver, M. (1996) Disability Politics: Understanding our past, changing our future. Sage Publications.

¹⁰⁶ Zarb, Gerry and Nadash, Pamela (1994) Cashing in on independence: Comparing the costs and benefits of cash and services, BCODP/PSI; Morris, J. (1993) Independent Lives? Community care and disabled people. The Macmillan Press.

¹⁰⁷ Kestenbaum, A. (1993) Making community care a reality: The Independent Living Fund 1988-1993, Independent Living Fund.

CILs also:

- run projects encouraging take-up of direct payments amongst marginalised groups;
- provide disability equality training;
- carry out consumer audits of services.

The National Centre for Independent Living (funded by the Department of Health) provides information, training, expertise and policy development on all aspects of direct payments and independent living. In July 2002, NCIL and the Association of Directors of Social Services (ADSS) signed a protocol setting out arrangements for local contracting of independent living services and stating that “the ADSS is committed to promoting independent living for disabled people and to supporting the development of Centres for Independent Living.”

Box 4.8: User led services have proved important in reaching out to Black and minority ethnic disabled people and other marginalised groups^{108,109}

Warwickshire Council of Disabled People appointed an Independent

Living Support worker to work with black and Asian communities. The organisation also employs a Black Disability worker to be involved in its campaigning and policy work. In 2000, 24% of people assisted to manage their own personal assistance were black or Asian people¹¹⁰.

Disabled people are best placed to take the lead in identifying their own needs and in identifying the most appropriate ways of meeting such needs

Many disabled people are able to self-assess their needs. Others may require advocacy support. In the few cases where resources have been allocated on the basis of self-assessment, there is no evidence that this has led to disproportionate demands on services. Indeed in one of the few evaluations of such an initiative, people used fewer hours of an on-call support scheme than had been originally envisaged¹¹¹.

Techniques such as Person Centred Planning enable the views and preferences of individuals to drive assessment of need. Such forms of assessment are effective both in terms of enabling disabled people to play their full part in society and make effective use of public

¹⁰⁸ Barnes, C., Morgan, H. and Mercer, G. (2001) *Creating Independent Futures*, The Disability Press.

¹⁰⁹ Rai-Atkins, A (2002) *Best practice in mental health advocacy for African, Caribbean and South Asian communities*, The Policy Press.

¹¹⁰ Butt, J. Bignall, T. and Stone, E. (2000) *Directing Support: Report from a workshop on direct payments and black and minority ethnic disabled people*, Joseph Rowntree Foundation/York Publishing Services.

¹¹¹ Zarb, G. (2001) *Haringey OnCall Support Service*, unpublished (available from the National Centre for Independent Living).

resources¹¹². Person Centred Planning is an important tool in the implementation of *Valuing People*¹¹³. With the right support and opportunities, disabled people with high support needs and/or communication difficulties can be included in this process, and can be in control of important and complex decisions¹¹⁴.

The Expert Patients programme (now being rolled out as a national programme covering a range of long-term conditions) has its origins in the Arthritis Self-Management Programme, which originated at Stanford University in the USA. This programme – where people with arthritis take the lead in running small group workshops with the aim of enabling people to better manage the symptoms of arthritis – has been shown to be highly effective in increasing the quality of people’s lives and reducing their dependence on health services¹¹⁵.

Box 4.9: Impact of the Expert Patient programme

Siobhan Long, an Expert Patient and course tutor for West Norfolk PCT, had had back, neck and foot problems for 14 years before she went on a pain management course and then an Expert Patients course. Now an EPP course tutor she feels she has a more equal relationship with health professionals. She has also achieved her goal of going back to work¹¹⁶.

The most effective responses are personalised to individual need

Enabling disabled people to take the lead in assessments and responses to their needs also helps create more personalised responses to those needs. And personalised responses mean that disabled people are more likely to live independent lives, playing a full part in family life, contributing to their local community and seeking employment or other valued activities.

Direct Payments are an important example of a mechanism that enables a personalised response to individual needs. Personalised services have also proved effective,

¹¹² McIntosh, B. and Whittaker, A. (2000) *Unlocking the future: Developing new lifestyles with people who have complex disabilities*, The King’s Fund.

¹¹³ Department of Health (2002) *Planning with People – towards person centred approaches*, Department of Health.

¹¹⁴ Edge, J. (2001) *Who’s in Control? Decision-making by people with learning difficulties who have high support needs*, Values into Action.

¹¹⁵ Barlow, J.H., Turner, A.P and Wright, C.C. A randomized controlled study of the Arthritis Self-Management Programme in the UK. *Health Education Research*, Dec. 15(6), 659-663.

¹¹⁶ http://www.natpact.nhs.uk/engaging_communities/communicating_within_communities/article_2/article2_05.php

and there is evidence that such methods can cost less than traditional services and can significantly improve outcomes in terms of the quality of an individual's life¹¹⁷.

Box 4.10: Case study of Direct Payments

"I was allocated support twice a day for one hour each visit. In reality I received 10–15 minutes morning and night. They said they had to send two people for health and safety reasons. Then I went onto Direct Payments and currently receive more hours for less money than it was costing before. But to me the important thing was it gave me choice and control over how my needs were met. Also, of course, one hour means one hour of support not a rushed 15 minutes with two people who often didn't communicate with each other and often didn't even acknowledge my existence¹¹⁸."

Box 4.11: Personalised responses to needs make it less likely that someone who has complex needs will require expensive residential or home-based services¹¹⁹

William had become increasingly dependent and unable to do things for himself over the years. He became violent and aggressive and a decision was made that a residential placement should be found. In the meantime a local support agency – experienced in working with people like William – put in a package of personalised support tailored to William's needs. During the first month, William required one-to-one support, including overnight and this cost £4,016 [1997 prices]. This gradually reduced as William was helped to do more things for himself and do the things he enjoys doing. His support package ended up costing £671.59 per month and he no longer needed to go into residential care, which would have cost considerably more. Providing William with personalised support had reduced his 'challenging behaviour', increased his ability to do things himself and therefore reduced the amount of support he needed¹²⁰.

¹¹⁷ Ryan, T. (1998) *The Cost of Opportunity: Purchasing Strategies in the housing and support arrangements of people with learning difficulties*, Values into Action; Zarb and Nadash (1998); Witcher et al (2000) *Direct Payments: the Impact on Choice and Control for Disabled People* Scottish Executive.

¹¹⁸ Personal communication as part of SU Consultation.

¹¹⁹ This is particularly important in the context of evidence of increasing numbers of young people with complex needs, including those with autistic spectrum disorder, coming through into adulthood.

¹²⁰ Example taken from: Ryan, T. (1998), 38-39.

Effective support addresses all aspects of someone's life, instead of fragmenting their lives across different services and/or funding mechanisms

Direct payments and ILF grants have been the main way in which disabled people have themselves taken a holistic approach to meeting their needs. This has been particularly important for people whose needs have been divided by health and social care organisations into 'health needs' and 'social care needs'. People who require assistance with managing their bladders and bowels, or regular physiotherapy to reduce spasms or prevent chest infections, have employed Personal Assistants to assist with these tasks and more general personal care tasks¹²¹. Disabled people often prefer this integrated approach to meeting their needs as they have control over when, how and by whom the assistance was provided. Such a situation does mean, however, that there is a shift of funding responsibility from health to social services/ILF with no equivalent shift of resources.

Holistic and rapid responses to people's needs can be cost-effective. For example, one local authority set up a pilot project involving a joint team of both social workers and occupational therapists who carried out assessments for people with physical impairments. Assessments

sought to address needs relating to both impairments and disabling barriers. Responses included not just social care services, aids and equipment, but also helping people to access other services, including health and community services. A comparison of expenditure resulting from these assessments with expenditure associated with separate social work and OT teams found that average expenditure on social care services was lower and average expenditure on equipment higher in the Joint Team. It appeared that a holistic approach to needs, combined with a rapid response one-off expenditure on equipment, reduced the need for social care services and, according to feedback from service users, was what they preferred¹²².

Disabled people need access to high-quality information and advice services, as well as to supported, independent advocacy

The most common services provided by disabled people's own organisations are information, advice and advocacy. Easy access to high quality up-to-date information is cited as a crucial service by most sections of the disabled population¹²³. People appreciate both the services provided by organisations such as Citizens Advice Bureaux and the advice and information provided by their peers and representative organisations.

¹²¹ Glendinning, C. et al. (2000) *Buying Independence: Using direct payments to integrate health and social services*, The Policy Press.

¹²² Morris, J. (2004) *Social Model Assessment Team Pilot Project: Report of Evaluation*. Essex County Council.

Advocacy and self-advocacy enable people to self-assess their needs and seek out the best ways of living independently¹²⁴. Advocacy and support for self-advocacy are often most effective when provided by representative organisations of disabled people and by disabled people themselves¹²⁵. An increasing number of local disability organisations, such as Centres for Independent Living, have service level agreements with local authorities to provide advocacy, information and advice.

The Government has recognised the value of advocacy services for people with learning disabilities by adopting the long-term aim of a choice of independent advocacy services in every area and by funding both citizen advocacy and self-advocacy¹²⁶.

Effective use of resources supports family and friendship networks and enable access to mainstream society

When people with learning disabilities are provided with individualised support, they are able to contribute to their families and local neighbourhoods. Research by Values into Action described, for example, how one man moved out of a residential home many miles away from his mother to his own home with support workers. Before, his mother struggled to visit him regularly; now he does his mother's garden and drops in every day to bring her the local paper¹²⁷.

Many disabled people who previously would not have been expected to work are now in paid employment, education or training. For example, people with 'severe mental health problems' have been assisted by South West London and St George's Mental Health NHS Trust to access employment and training: many of these people would previously have attended day centres¹²⁸. Following the Social Exclusion Unit's report on mental health, mental health services are

¹²³ National Autistic Society (2003) *Autism: the demand for advocacy*, NAS; West Norfolk Disability Information Project (1997) *Closing the Net: A users view of Disability Information in West Norfolk*, West Norfolk Disability Information Project; Beresford, B. and Sloper, T. (1999) *The information needs of chronically ill or physically disabled children and adolescents*, Social Policy Research Unit, University of York; Wates, M. 2003. *It shouldn't be down to luck: Results of a DPN consultation with disabled parents on access to information and services to support parenting*, Disabled Parents Network.

¹²⁴ Ward, L. (1999) *Innovations in Advocacy and Empowerment*, Lisieux Hall Publications.

¹²⁵ Morris, J. (1993) *The Independent Living Advocacy Project*, Spinal Injuries Association; Bird, A. (2000) *GLAD Self-advocacy Project*, Greater London Association of Disabled People; Greene, M. (1999) *Over to us ... A report of an advocacy project working with young disabled people living in residential institutions*, Greater Manchester Coalition of Disabled People.

¹²⁶ These initiatives are part of the national Learning Disability Strategy, *Valuing People*.

¹²⁷ Ryan, T. (1998) *The Cost of Opportunity: Purchasing strategies in the housing and support arrangements of people with learning difficulties*, Values into Action, pp. 56-58.

¹²⁸ Rinaldi, M., McNeil, K. Firn, M., Koletsi, M., Perkins, R., and Singh, S.P. (forthcoming) 'What are the benefits of evidence based supported employment for people with first episode psychosis', *Psychiatric Bulletin*.

working with Jobcentre Plus to improve the employment opportunities of mental health service users¹²⁹.

4.4 Recommendations for action

“Mainstreaming” disability issues

When the duty to promote disability equality contained in the Disability Bill comes into force, public authorities will be legally obliged to scrutinise all policy initiatives and proposed legislation to ensure that whenever these could have a material impact on disabled people’s lives, the needs and circumstances of disabled children and adults are properly addressed, and that such initiatives give due regard to the need to promote disability equality. This will be the collective responsibility of all government departments, working under Disability Rights Commission guidance. The Strategy Unit welcomes this implication of the Public Sector Duty.

Appropriate mechanisms should be used to encourage “mainstream” community and other public services to increase take-up and use by disabled people. Cross-cutting targets should be used to encourage effective joint-working.

Working with disabled people and their organisations to achieve the vision

Recommendation 4.1: Modelling good practice

From 2005 onwards, government departments should model good practice in involving disabled people.

A key element of the public sector duty to promote disability equality is the requirement that public authorities involve disabled people in their compliance with the duty’s requirements. The DRC will be producing guidance to help public bodies to respond.

All targets, standards and agreements substantially affecting disabled people should be set in consultation with disabled people and their organisations.

A User Involvement Protocol should be developed, in consultation with disability organisations, for all government departments. The organisational arrangements for developing this protocol are discussed in Chapter 8.

This protocol should include:

- early involvement of disability organisations in policy development;
- seeking information from disability organisations on the impact of policy options;
- agreeing criteria for which organisations to involve, in line

¹²⁹ Social Exclusion Unit (2004) Mental Health and Social Exclusion, ODPM.

with the public sector duty to involve disabled people;

- payment of fees and expenses for involvement; and
- addressing all access needs when involving disabled people and their organisations.

**Recommendation 4.2:
User involvement protocols**

By 2006, user involvement protocols for both commissioning and monitoring services should be developed by public bodies, in consultation with disabled people. Local authorities should develop a protocol for the whole authority, not one per individual function.

The development and use of the protocols will be part of existing service improvement initiatives. Registration and inspection bodies will be asked to develop further their involvement of service users, and to use standards relating to user involvement when registering and inspecting services.

**Recommendation 4.3:
User-led organisations**

By 2010, each locality (defined as that area covered by a Council with social services responsibilities) should have a user-led organisation modelled on existing CILs. DH and ODPM to lead.

Local organisations, run and controlled by disabled people¹³⁰, will be a vital part of the implementation of a new approach to supporting independent living. Funding for the services provided will come from Service Level Agreements with health, social services, DWP and other agencies, and from spot purchasing of services such as disability equality training and consumer audits. The exact nature of the services provided and their relationship with statutory agencies will vary according to local circumstances but, at a minimum, the organisations should provide:

- information and advice;
- advocacy and peer support;
- assistance with self-assessment;
- support in using individual budgets (including cash payments) to meet needs;
- support to recruit and employ personal assistants;
- disability equality training; and
- consumer audits of local services.

The case should be explored for additional resources to be bid for from Spending Review 2006 to facilitate the development of a national network of user-led organisations and to support high quality services. As existing CILs

¹³⁰ The defining characteristics of these local organisations would be those set out in the protocol for contracting direct payments support schemes agreed between the National Centre for Independent Living and the Association of Directors of Social Services in July 2002.

provide the same service for older people using direct payments as they do for people below retirement age, it would be expected that the expansion of user-led organisations would similarly provide a service to disabled people of any age.

Personalising responses to needs and maximising choice and empowerment

Recommendation 4.4: Supporting independent living

DH supported by DWP, DfES and ODPM should – by 2012 – work towards a new approach to supporting independent living, which delivers support, equipment and/or adaptations in a way that:

- addresses all aspects of needs for support and/or equipment or adaptations;
- is personalised according to individual need and circumstances;
- is underpinned by the principle of listening to disabled people and acknowledging their expertise in how to meet their needs;
- maximises the choice and control that people have over how their additional requirements are met;
- provides people with security and certainty about what level of support is available;

- wherever possible, minimises the disincentive to seek paid employment or to move from one locality to another; and
- uses existing resources to maximise social inclusion.

The next section sets out a piloting process for a new system of supporting independent living for disabled people.

For disabled people to be supported in independent living, a range of individual needs need to be met. These needs are currently addressed through a number of different systems and budgets within and beyond social care, including: community care resources; housing adaptations; independent living; advocacy; and employment and education support. Government should aim for a situation where resources are used to increase independence as effectively as possible, and avoid situations where a failure to meet needs from one budget results in increased expenditure from another.

While Direct Payments have delivered significant choice and control for some people, they are not suitable for everyone. Moreover, the fragmentation of people's needs across different budgets means that Direct Payments are not always sufficient to deliver a personalised and holistic response to individuals' needs.

This report therefore proposes that different sources of funding should be brought together in the form of individual budgets – while giving individuals the choice whether to take these budgets as cash or as services. The overall aim would be to enable existing resources to be allocated and services delivered in ways that personalise responses to need, and give disabled people choice over how their needs are met.

This report envisages that national roll-out could take place by 2012, subject to there being clear evidence on the preferred design of the system, and subject to the availability of appropriate resources to initiate change.

The new system would be underpinned by a number of key principles:

- a simplified resource allocation system, including ‘one stop’ assessment and information provision, enabling available resources to be allocated effectively according to need¹³¹;
- individuals should be able to take some or all of their budget as a cash payment and/or to have control over the budget (with support if necessary) without actually receiving the cash;
- budgets would be available to meet agreed eligible needs but under the control of the person

needing the support, with assistance if required;

- self-assessment, with advice/information or advocacy support where required;
- eligibility based on requirements arising from disabling barriers (e.g. cash payment for taxis when public transport is inaccessible) and additional requirements associated with impairment (e.g. voice-recognition software to enable someone to read text at home and work);
- access to advocacy where this is needed, with qualifications and standards for independent advocates.

The new system would include all budgets that enable different types of support needs to be met, including personal care; family roles and responsibilities; access to the community, employment, voluntary work, training and education, and leisure activities; and include equipment, personal assistance, transport, adaptations and advocacy.

Budgets that should be considered for inclusion are: community care resources and social services expenditure on equipment and minor adaptations; Independent Living Funds; Disabled Facilities Grant; Family Fund; and Access to Work. Individual budgets should wherever possible minimise the

¹³¹ For example, based on the approach being tested out by the In Control pilots which are part of the implementation of Valuing People. www.selfdirectedsupport.org

disincentive to move from one local authority area to another. And there should be a national charging policy which so far as possible minimises financial disincentives to seek paid employment¹³². There should also be a separation of the role of assessment from the role of determining eligibility¹³³.

The new system would require a cultural shift so that social care professionals are working to promote self-directed support. Such a shift would be encouraged by closer working relationships between health and social care organisations and organisations of disabled people.

Box 4.12: Equipment or support which is portable should belong to the individual disabled person and not to the employer

The Expert Group on Independent Living told the Strategy Unit that, while employers might need advice about reasonable adjustments and should be responsible for general changes to do with access (e.g. ramps, loop systems, Clearprint standards for written communications), support/assistance/equipment personal to a particular individual should be delivered by the same system that provides the assistance and equipment someone needs when they are not at work. Existing Access to Work rules do

allow JobCentre Plus to buy out the employer's share of an individual's equipment if the user needs that equipment for another job. Importantly, however, the equipment does not belong to the individual and there is no integration in the support or equipment needed both in and out of the workplace, because of different budgets and delivery systems.

This report makes some specific proposals concerning Access to Work, and the role of supported employment agencies and DEAs in Chapter 7. The proposals relating to Access to Work are relevant to proposals concerning independent living. Any equipment or support which is portable and could be used in any employment context should belong to the individual disabled person and not to the employer. Such support or equipment should be part of individual budgets. This would prevent disputes between health, social services, and DWP about funding responsibilities and would also increase disabled people's ability to move between one job and another. It would also reduce the number of situations where someone does not get the support or equipment they need until some weeks or months after they have started a job.

¹³² This is already the situation in the current charging policy for community care services but (a) it will be more clearly stated in revised guidance and (b) it will need to be extended to the means test for disabled facilities grants and for residential care.

¹³³ This feature is being tested out by the In Control pilot in Lincolnshire.

Early pilots are needed to assess what sort of system could deliver this new approach

**Recommendation 4.5:
Piloting individualised budgets**

An evidence base for individual budgets – bringing together various sources of funding, services, equipment and adaptations – should be developed over the next three years, within existing resources and working with local organisations already making progress in this area.

The case should be considered for submitting a Spending Review 2006 bid to enable further pilots – any new fund should be on the basis of an ‘invest to save’ approach, which would provide up-front resources to facilitate further evidence-building and to introduce the changes required by the new system.

DH, supported by DWP and ODPM, from early 2005 onwards.

The new approach to supporting independent living will represent a step-change from current approaches. It is therefore proposed that possible organisational structures for delivering individual budgets should be piloted and evaluated. Two approaches are proposed.

- In the short term – over the next three years – DH¹³⁴ should take the lead, working with other government departments (in particular ODPM and DWP), to identify local authorities which are already working towards the agenda set out in this chapter, and find ways of using existing work to build a coherent evidence base. One promising route would be to work with some of the Local Area Agreements (LAAs) pilots, being driven by local authorities and local strategic partnerships (LSPs), subject to complementarities with locally-agreed outcomes and without imposing additional burdens.
- DH should also take the lead – with input from ODPM and DWP – in considering the merits of a possible bid for Spending Review 2006 funding on an ‘invest to save’ basis. Such funding would enable a more extensive programme of pilots to be undertaken across local authorities, and be aimed at improving the evidence base and introducing the different elements of the new approach to supporting independent living. The intention would be to test whether the new approach can indeed improve outcomes for service users, while improving the efficiency of service provision. It would be important to ensure there is systematic service user involvement.

¹³⁴ Stephen Ladyman, Parliamentary Under Secretary of State, Department of Health has already discussed many of the issues covered in this chapter. See, for example, PUSS speech to the Learning Disability Today Event on 24th November 2004.

The piloting process will need to address questions such as:

- Is the use of individual budgets cost-effective?
- How can we make sure that those holding individual budgets have good quality services/equipment to choose between?
- Are individual budgets appropriate for a range of different needs and circumstances?
- What level of support is required to use individual budgets?
- How can we ensure equitable treatment for people who cannot manage an individual budget even with support?

The piloting of individual budgets could also test whether early intervention with people who are not eligible for services would be cost-effective in the long run, by managing needs proactively before they increase.

**Recommendation 4.6:
The role of local authorities**

Local authorities should have a key strategic role in delivering the new system.

ODPM to lead, with support from DH, from 2005 onwards.

The forthcoming Green Paper on Adult Social Care will initiate a consultation on the role of local authorities in planning services for

disabled people. It may be that more than one model of delivering the outcomes is shown to be effective. However, irrespective of the outcomes of the pilots, local authorities are likely to continue to have the following roles:

- strategic planning to meet the needs of their disabled population;
- building bridges between health, education, social care providers, housing, employment support, local and regional economic development activity (including neighbourhood regeneration);
- with partner agencies, using their commissioning role to enable the development of services to respond to disabled people's use of individual budgets;
- putting in place easier access to information;
- developing community capacity and cohesion; and
- complying with their public sector duty to actively promote equality of opportunity for disabled people.

Social services authorities, and other social care agencies, are likely to continue to have a key role in bringing about service improvements, so that disabled people have a real choice when using their individual budgets to meet their needs. For example, a

social care agency could set up block contracts with service providers with a guarantee of minimum volume, but on a call-off basis. The social care agency could then 'market' these contracts to those holding individual budgets. Such an arrangement would not be without risks for the agency – but would capitalise on the advantages of block contracts while providing a significant incentive for quality services.

**Recommendation 4.7:
Information and advice**

DH, by 2006, should assess existing information and advice provision, and consider the case for submitting a Spending Review 2006 bid to address any gaps identified.

The efficiency of any new system of individualised budgets will need to be promoted by ensuring that individuals have access to high-quality information and advice about services and equipment. The type of information needed is likely to include:

- information about entitlements and how to find your way around the system;
- local and national information about services, equipment, advocates and service brokers (including user-friendly guides to services inspected by CSCI); and

- local and national users' views of services, equipment, and other support.

Investment in services for disabled people should be determined by the aim of enabling disabled people to fulfil their roles and responsibilities as citizens

Investment in public services should be switched from services that create dependency, towards services that enable disabled people to fulfil their roles and responsibilities as citizens. This will build on the existing policies concerning mental health day services and the implementation of Valuing People by extending this principle to all public investment aimed at meeting the needs of all disabled people.

**Recommendation 4.8:
Supporting disabled people to help themselves**

DH should:

- introduce, after consultation, a more appropriate definition of 'disabled person' for the purposes of community care services that is consistent with the DDA definition and takes account of the implications for disability across all ages. If the change requires legislative change it should be incorporated within other planned legislative amendments;
- in 2005, consult on the merits of a 'right to request' not to live in a residential or nursing care

setting, taking full account of the particular issues faced by older people, and considering the financial, organisational and legal implications of both the status quo and alternative options. This 'right to request' would require service providers to make explicit the reasons behind their decision, including cost considerations;

- by end of 2006, analyse the costs and benefits of amending charging policies for residential care to minimise disincentives to paid employment and if appropriate, make these amendments in the light of the evidence; and
- by 2006, consider making the case for 'invest to save' resources to be made available from SR2006 to enable the development of community based resources to meet the needs of children and adults who would otherwise be placed in residential care (see also Chapter 5).

The case will need to be made for extra resources to initiate some of the changes required to move towards a new approach to supporting independent living. But the analysis carried out for this report suggests that any extra resources could be seen as a form of social investment – there is good reason to expect that the net

present value of this investment in independent living should be strongly positive. A more effective targeting of support will reduce benefit dependency, promote opportunity and enable more people to take up their responsibilities in contributing to society¹³⁵.

Improving housing opportunities for disabled people

Recommendation 4.9: Improving the DFG

ODPM should consider, by 2005, reform to the DFG in the light of the forthcoming findings of the review. In particular it should consider whether changes to existing eligibility criteria could mitigate disincentives to paid employment.

As discussed in Section 4.2, a failure to make transparent the costs resulting from a delay, or failure, to carry out adaptations – or provide equipment – can lead to greater public expenditure than would otherwise be necessary, as well as having a significant impact on disabled people's quality of life.

The current policy review of the DFG has commissioned an extensive research project being undertaken by Bristol University to examine the current operation of the DFG programme and to make recommendations for improvement in line with the Review Group's

¹³⁵ The DRC and SCIE are working on a cost benefit analysis of independent living which should provide additional evidence.

terms of reference. This will address many aspects of the costs and benefits of delivering home adaptations including alternative options such as providing more moving grants. It will also provide some evidence of the implications for other government programmes of not providing DFGs.

There is at present no effective process for considering the implications of failing to provide – or of delays in providing – adaptations, on other programmes and budgets. This is illustrative of wider problems with budget and programme boundaries. A lack of transparency occurs across many of these boundaries at both national and local level. This can result in unnecessarily high costs and poorer outcomes for disabled people. Making such relationships transparent, and taking them into account in decisions about budget allocations, should enable a more cost-effective approach to supporting independent living. If this can be done for the funding of adaptations, important lessons may be learnt for extending this approach to other areas.

**Recommendation 4.10:
Including disabled people in
housing initiatives**

ODPM, from 2005 onwards, should work with the DRC, organisations of disabled people, and the Housing Corporation to ensure that investment in initiatives such as neighbourhood renewal,

housing market renewal, low-cost home ownership and key worker housing schemes improve housing opportunities for disabled people.

Most aspects of housing policy impact on the life chances of disabled people. The public sector duty to promote disability equality will require future policies to be scrutinised to ensure they promote, rather than diminish, disabled people's housing opportunities. The public sector duty means that a proactive approach will be taken to promoting equality of opportunity for disabled people in terms of their housing experiences.

Better use should be made of the stock of designed and adapted housing to ensure that disabled people are enabled to access housing that is appropriate to their needs. The Government has recently given a commitment to issue statutory guidance on how this can be achieved in the social housing sector.

**Recommendation 4.11:
Lifetime Homes**

As part of the review of building regulations announced in spring 2004, ODPM should commission work, by 2006, to review the effect of the 1999 guidance on access to dwellings, and to consider the feasibility of incorporating Lifetime Homes standards, updated as necessary, into the guidance on Part M of

the Building Regulations. Any amendment would be subject to a Regulatory Impact Assessment and the outcome of public consultation.

There is widespread acceptance that key features of the current Lifetime Homes standards are popular with householders, can be provided for minimum cost, and save money to both the private and the public purse in the long run. However, the standards were written some years ago and need updating.

Recommendation 4.11 would enable concerted action on an issue which urgently needs tackling, given the projected increase in new-build over the coming years.

Personalised and integrated approaches to transport opportunities

Recommendation 4.12: Transport and independent living

2005 onwards, DH to encourage local authorities to include transport and mobility needs of disabled people in assessments within the new system of promoting independent living.

Independent living assessments should include looking at transport needs, some of which could be met within individual budgets (for example where someone needs 'mobility training' or confidence building to use public transport).

Where barriers relate to transport infrastructure or service provision, the forthcoming public sector duty to promote disability equality will require Local Strategic Partnerships, 16 – 19 Transport Partnerships and Rural Transport Partnerships to pay due regard to this information, and to remove these barriers in carrying out their functions.

Recommendation 4.13: Transport and local authorities

The Department for Transport should, from 2005 onwards, encourage local authorities to play a strategic role to ensure that disabled people do not experience barriers at any stage of the journeys they need to make.

Local authorities should be encouraged to use the framework provided by the Accessibility Planning Guidance, to address the travel experiences of disabled people, including those whose transport needs relate not to the physical environment but to the way a service is provided. Disabled people and their organisations should be fully involved in the monitoring and implementation of Accessibility Strategies (required as part of Local Transport Plans) through the implementation of the User Involvement Protocols and consumer audits carried out by local CILs.

Chapter 5: Early years and family support

Summary

The early years are a critical period for disabled children. Child development and future life chances – as well as those of siblings – are critically affected by the support and services received by young disabled children and their families. Targeting support at these families will also play a major role in helping to eradicate child poverty.

Families of disabled children should have access to the individualised budgets described in Chapter 4, providing choice and empowerment across multiple transitions. Pilots for the way in which these individualised budgets will work should include families of disabled children – and, in due course, a new system should be rolled out nationwide.

Focusing on the current situation, the key challenge is to make sure that disabled children and their families benefit from wider reforms in early years' policy. Future government policy should enable young disabled children and their families to access 'ordinary' lives, through effective support in mainstream settings. Services – both specialist and mainstream – should be designed to meet families' needs through early family support. Services also need to be 'fit for purpose' in terms of workforce, joint working and information about disabled children's needs.

This points to the need for progress in a number of areas, for example:

- disabled children and their families should have timely access to the equipment they need, when and where they need it;
- all families with a disabled child who need it should receive childcare provision that is sustainable, high quality, flexible, affordable and accessible; and
- a key worker should be in place for all families with high needs to provide information, improve communication and coordinate multi-agency interventions.

This chapter specifically addresses the needs of young disabled children under five years and their families, though connections are made between spend on older children and younger children. Section 5.1 outlines briefly the current situation facing families with young disabled children at the moment. Section 5.2 looks at what needs to be done to enable families with disabled children to access 'ordinary' lives. Section 5.3 addresses services that meet families' needs, including early family support, equipment and housing. Section 5.4 contains proposals to ensure that services for disabled children are 'fit for purpose' through a trained workforce, joint-working and shared information.

5.1 What is the current situation?

Chapter 2 has described the changing population of young disabled children – disabled children's needs are increasing, with implications for the range of support and the configuration of services they require.

Disabled children are more likely to live in poverty than non-disabled children

The Government's goal to halve child poverty by 2010 and eradicate it by 2020 will require specific

targeting of families with disabled children. Children from lower income households are more likely to report long standing illness or disability¹³⁶ and mental health issues¹³⁷. This reflects a two-way relationship between low income and impairment.

- Poverty can increase the risk of a child having an impairment. For example, children born to low income families are more likely to be low birth weight, with associated risks of future health problems, including delayed motor and social development¹³⁸. Babies with very low birth rates (under 1,500 grams) are at increased risk of long-term impairment¹³⁹.
- Having a disabled child can also mean that parents find it harder to maintain full-time employment, their housing can be inadequate for their child's needs, and expenditure on basic needs is increased. Families with disabled children can experience negative attitudes from others about themselves and their child. All this can lead to poverty and social exclusion of the whole family, including siblings¹⁴⁰.

The first few years are critical to the life chances of all children; for disabled children there can also be

¹³⁶ Health Survey for England (2002) *The Stationery Office*.

¹³⁷ Meltzer H et al (2000) *The mental health of children and adolescents in Great Britain*.

¹³⁸ For example, Hediger, Overpeck, Ruan and Troendle (2002) 'Birthweight and gestational age effects on motor and social development', *Pediatric and Prenatal Epidemiology*, 16.

¹³⁹ Hack, Klein and Taylor (1995) 'Long-term developmental outcomes of low birthweight infants', *The Future of Children: Low birth weight 5* (Spring 1995).

major impacts on the life chances of their families. The result is a group of children with reduced life chances and multiple sources of disadvantage, living in socially excluded families.

There is unmet need among minority ethnic families with disabled children

The levels of unmet need for services by minority ethnic parents with disabled children have been found to be higher than for white families¹⁴¹. There is also some evidence that minority ethnic families with disabled children have lower take-up of benefits such as Disability Living Allowance¹⁴².

One aspect of minority ethnic families' interaction with service providers is language, and there are shortages of interpretation facilities in some areas. There are also ways in which assumptions that minority ethnic families receive high levels of family support can affect the level of services offered to them. And services can also be delivered in a way that makes it difficult for certain families to take them up (for example, provision of overnight support for children out of the home, rather than in the home).

Early years policy is expanding, the challenge is making sure disabled children benefit from wider reforms

Early years is a dynamic policy area with many new initiatives aimed at bolstering development and support for very young children. Given the importance of early years support in promoting life chances, these policies are welcome. More evidence is required, however, on the impact of these policies on disabled children.

Box 5.1: Summary of key early years and family support policies

The overarching framework for children's policy comes from the **Every Child Matters** Green Paper, and the subsequent **Children Act 2004**, and the **Children Act 1989**.

The **Children's National Service Framework (NSF)**, published in September 2004, sets out a ten-year programme for sustained improvement in children's health and well-being through standards for the care of children, young people and maternity services. Standard 8 of the NSF has a particular focus on disabled children and young people and those with complex health needs.

Sure Start includes a range of childcare, early years and

¹⁴⁰ The recommendations in Chapter 7 aim to improve the employability of disabled adults, a group which includes disabled parents. Disabled parents, as well as parents of disabled children, face barriers to employment and improving their life chances. Some families will include disabled parents and children although there is little specific data on this group.

¹⁴¹ Chamba, R et al (1999) *On the edge: Minority ethnic families caring for a severely disabled child*. Joseph Rowntree Foundation.

¹⁴² Chamba, R et al (1999).

integrated services aimed at achieving better outcomes for children, parents and communities. Children's Centres will build on Sure Start local programmes, neighbourhood nurseries and early excellence centres and will provide families with pre-school children in the most disadvantaged areas integrated early education and childcare, family support, health and advice on employment and training opportunities. There will be 3,500 children's centres by 2010.

Children's Trusts are a non-statutory aspect of local government that will, in partnership with the voluntary and community sector, commission children's education, social services, certain health services and Connexions. Government has recommended there to be one in every area by 2008.

Together from the Start is a set of guidance for professionals working with disabled children (up to three years) on how to deliver services, diagnose impairments earlier and work with families.

Early Support is a programme aiming to provide family support to very young disabled children through service integration, improved information sharing and assessments, and support from key workers, using the principles of Together from the Start.

Early education has been expanded with a free, part-time nursery place available for three and four-year-olds in England. A pilot has been announced to extend this to 12,000 two-year-olds in disadvantaged areas.

Family Fund provides grants to families with severely disabled children to help with additional costs.

Removing Barriers to Achievement – is the Government strategy for special educational needs (SEN) to enable all children to benefit from education. Special Educational Needs Coordinators (**SENCOs**) have a key role in helping to ensure children's needs are identified and addressed through specialist support.

There is a free, national **Telephone Helpline** (0800 808 3555) run by Contact A Family and funded by government, to provide information to families on all medical conditions and local and national support groups.

The Strategy Unit report builds on these existing early years and family support policies, including the standards set in the Children's National Service Framework.

5.2 Accessing 'ordinary' lives

Overarching vision for accessing 'ordinary' lives: by 2025, all families with disabled children to have access to high-quality, affordable childcare and early education.

All young children and their families have needs relating to their well-being and development. These change quickly over the course of a young life – from newborn baby to toddler to young child. Much of the focus for very young children is the home environment itself, but 'ordinary' lives for young children also means interacting with other children, parents and extended family either in or beyond the home through play, early education and care.

The individualised budgets approach described in Chapter 4 should help to make sure that these needs are met, if applied to the services provided to disabled children and their families. These family budgets could holistically address the family's needs arising from their child's impairment – meeting their needs and enabling them to access 'ordinary' lives simultaneously. The budget could encompass housing, transport, equipment, childcare and support services and take into account the total impact of the child's impairment on family life, including siblings and parents.

The extension of this approach into childhood would need to take full account of the structure of children's

services (and the legal role of parents in the care of young children) and the role of education in children's lives. It should also be consistent with other national developments towards rationalised funding streams.

Recommendation 5.1: Individualised budgets

The individualised budgets approach described in Chapter 4 should, in principle, be extended to families with disabled children.

The mechanisms, costs and benefits will need to be investigated through pilots coordinated with those for adults. The design and timing of these pilots will also need to be carefully coordinated with the roll-out of wider changes to the landscape of children's services.

DH with support from DfES, DWP and ODPM. By 2012, subject to evidence and resources.

In parallel with developing individualised family budgets, there are many other areas where progress needs to be made in the short to medium term.

A lack of childcare and early education means that many families with disabled children are socially and economically disadvantaged.

Disabled children and their families have proportionately less childcare and early education provision than

other groups¹⁴³. Evidence indicates that this is due to a lack of available places for disabled children and to the high costs of existing places. A lack of childcare and early education has multiple implications for families, including siblings, because families become disproportionately home-based with impacts on income and on social exclusion. There are also impacts on the child's development.

There is particular shortage of good-quality, affordable childminders accessible to disabled children¹⁴⁴. Childminders lack training to meet disabled children's needs¹⁴⁵ and those who do look after disabled children may also earn less because they can look after fewer children at one time, or provide a service which is unaffordable for many families. School-based provision is more readily available, but 62% of school providers in one survey could only offer a place to one disabled child at a time¹⁴⁶.

There has been high take-up of government's free part-time early education places – 82 places per 100 three-year-old children have been taken up and 98 places per 100

four-year-old children have been taken up¹⁴⁷. However, there is some anecdotal evidence that some of the hardest to reach families, including those with disabled children, are not accessing these places.

Childcare and early education help children's development, family income and social inclusion

The Early Years Transition and Special Educational Needs (EYTSSEN) and Early Provision of Pre-school Educational (EPPE) projects demonstrated benefits from high-quality pre-school educational activity, especially if combined with care and started before three years¹⁴⁸. These interventions had a positive impact on young children's cognitive development, including those 'at risk' of developing SEN¹⁴⁹. Indeed, children who did not go to pre-school were more 'at risk' of SEN. The research also showed that different types of SEN are helped by different types of pre-school provision which makes early identification of SEN important.

The Government is already committed to free part-time early education places for all three- and four-year-olds. There will also be a

¹⁴³ National Audit Office (2004) *Early Years: Progress in developing high quality childcare and early education accessible to all*, Report by the Comptroller and Auditor General.

¹⁴⁴ National Audit Office (2004).

¹⁴⁵ National Audit Office (2004).

¹⁴⁶ National Audit Office (2004).

¹⁴⁷ National Statistics (2004) "Provision for Children Under Five Years of Age in England: January 2004 (Final)"

¹⁴⁸ Sylva et al (2003) *The Effective Provision of Pre-School Education (EPPE) Project : Findings from the Pre-school Period*, Institute of Education; Sammons et al (2003) *The Early Years Transition and Special Educational Needs (EYTSSEN) Project*, DfES.

¹⁴⁹ Although there is significant overlap between children with a SEN and disabled children, these two groups are not the same. This is discussed in Section 1.4.

pilot to extend free part-time early education to 12,000 two-year-olds in disadvantaged areas. The challenge will be to ensure that disabled children are fully included in these commitments.

Box 5.2: Good practice example of a mainstream nursery school

A mainstream nursery school in southern England offers priority places to children with SEN. The school creates an inclusive environment so that every child can learn through play.

It has a toy library, funded by the Early Years Development and Childcare Partnership (EYDCP), which provides activity packs to guide parents on how to play with their child to promote their development. The toys focus on specific issues such as speech and language or motor skills.

But there are problems even in this beacon school. The school SENCO needs half a day per week to liaise with other professionals such as health visitors and child development teams, but this is often unavailable owing to funding constraints. There is no funding to create a dedicated 'quiet' room, which restricts the school in meeting certain children's needs. There is also funding uncertainty about the toy library.

There is widespread evidence on the benefits of high-quality childcare¹⁵⁰, and the Child Poverty Review 2004¹⁵¹ and the Government's ten year strategy on childcare¹⁵² states that the provision of good quality, accessible childcare will be enhanced. The Sure Start Unit has a new set of targets, as a contribution to reducing the proportion of children living in households where no one is working, by 2008: to increase the stock of Ofsted-registered childcare by 10%; increase the take-up of formal childcare by lower income working families by 50%; and introduce, by April 2005, a successful light-touch childcare approval scheme.

In the future, there will be more sites at which childcare is provided including Neighbourhood Nurseries, Children's Centres and extended schools providing 'wraparound' care after school hours. There are moves towards further integration of early education and childcare, and the Government has published a 10 year strategy for childcare. The challenge again will be to ensure that disabled children can access these facilities.

¹⁵⁰ See, for example, Melhuish, T. (2003) *A literature review of the impact of early years provision on young children, with emphasis given to children from disadvantaged backgrounds*. Prepared for the National Audit Office.

¹⁵¹ HM Treasury (July 2004) Child Poverty Review.

¹⁵² http://www.hm-treasury.gov.uk/pre_budget_report/prebud_pbr04/assoc_docs/prebud_pbr04_adchildcare.cfm

Recommendation 5.2: Childcare and early education

As part of the Government's existing commitment to early education, DfES should ensure that all three- to four-year old disabled children and children with SEN can access the free part-time place provision (currently two and a half hours for five sessions for 33 weeks) by 2010, and that providers will have adequate access to a fully-supported early years SENCO.

As part of the 10-year strategy for childcare, the Sure Start Unit should ensure, by 2015, all families with a disabled child under five years can access high quality, flexible childcare.

DfES should ensure that the extension of 'wraparound' school-based childcare is fully accessible by families with a disabled child over five years old, as this is rolled out.

The rhetoric of mainstreaming needs to be followed up by specific action to include disabled children

Many families with disabled children would like to access mainstream services – including early education, play and childcare – with adequate support where needed. This not only benefits many disabled children, enabling them to take part in activities in the same way as their non-disabled peers, but non-

disabled children also benefit from growing up in a diverse and inclusive environment.

There is widespread, but often anecdotal, evidence that families with disabled children are facing barriers to accessing mainstream services and activities. The barriers include a lack of outreach by mainstream services and a lack of capacity in some mainstream services to meet disabled children's needs (or a perception by the services that they cannot meet these needs). The specific capacity gaps include workforce limitations and a lack of suitable premises and equipment. Another barrier is a lack of information for parents about services and activities that are available.

In a school context, there is greater awareness of the benefits of inclusion but variable quality of teaching of pupils with SEN. The inclusion agenda has had little impact on the proportion of children with SEN in mainstream schools, or on the range of SEN needs catered for. Few schools systematically evaluate their provision for children with SEN¹⁵³.

It therefore remains uncertain whether the new landscape of mainstream children's services – in the public, voluntary and community sectors – is meeting the needs of disabled children. In particular, there remains a lack of systematic evidence on the impacts of

¹⁵³ Ofsted (2004) "Special educational needs and disability: towards inclusive schools".

mainstream services and activities on disabled children, or whether they are indeed being effectively included.

Box 5.3: Mainstreaming and the DDA

Enabling disabled children and their families to be included in mainstream life is beneficial for them and for the rest of society. The **Disability Discrimination Act 1995 Part 3** reflects this by stating that disabled children are entitled to reasonable access to goods, facilities, premises and services.

Since October 2004, services provided by government departments, local authorities, charities and the voluntary sector, hospitals and clinics, shops, pubs, banks and hotels have been required to make anticipatory reasonable adjustments to include disabled children.

The **SEN and Disability Act 2001** introduced a new **Part 4** to the Disability Discrimination Act. This applies the DDA duties to education and associated services, including early years. Part 4 requires all schools to make reasonable adjustments so that disabled pupils have access to the curriculum, physical environment and information. All early years provision is now covered by either Part 3 or Part 4 of the DDA.

The public sector duty in the draft **Disability Discrimination Bill** will

mean that all public authorities will be required to give due regard to the need to promote equality of opportunity for disabled people as they plan and deliver policy initiatives. This will be to ensure that whenever these could have a material impact, the needs and circumstances of disabled children and adults are properly addressed. The duty will also require disabled children and young people to be involved in the development and delivery of policy.

In Scotland, the **Education (Additional Support for Learning) (Scotland) Act 2004** requires education authorities to provide additional support to disabled children under three years who have been referred by a health board.

Recommendation 5.3: Evaluation of children's services

DfES should, from 2005 onwards, require all national evaluations of children's services – such as the National Evaluation of Sure Start (NESS) – to assess impacts on families with disabled children, including families from minority ethnic communities, and recommend specific actions to address barriers to their inclusion.

DH and DfES to develop guidance, from 2005 onwards, for evaluations of children's services

carried out at a local or regional level to ensure they take account of the needs of the local disabled children's population.

5.3 Meeting families' needs

Overarching vision for meeting families' needs:

by 2014, all families with young disabled children to have the level of family support they need to enable them to function as a family and to care for their disabled child.

Families with young disabled children have additional needs. These needs may be specific to the child – such as assistive technology – or be part of the wider implications of having a disabled child – such as need for home-based support. Importantly, different families will have different levels of need, from relatively little – such as signposting to information sources – to needs that are significant and long-term.

Many families with disabled children are struggling owing to lack of family support

Families with disabled children often face particularly high stress and family breakdown owing to the increased pressures of looking after a disabled child. If a child has

difficulty in sleeping or in behaving in a way that allows them to join in with mainstream activities, parents can often face significant anxiety and social isolation¹⁵⁴. Parental stress resulting from a lack of local support has been given as a reason for children being placed in residential provision¹⁵⁵. Sleep problems can also impact on the child in terms of lack of concentration and increased probability of behavioural difficulties during the day¹⁵⁶. Of 1,100 parents with a severely disabled child, 56% said that 'help with behaviour' is a key need and 61% of these said the need was unmet or partially met¹⁵⁷.

Parents would also like support with everyday activities for themselves, such as having time to have a bath, go shopping and sleep without disturbance, especially if their child has very high levels of need or if they have more than one disabled child¹⁵⁸. Sometimes what families want is an extra pair of hands to enable them to do things as a family. In addition, siblings' own quality of life may be adversely affected if parents are not sufficiently supported. Siblings may also need special attention themselves.

¹⁵⁴ As many as 45% of children in special schools can wake up regularly at night compared with 13% of children in mainstream schools.

¹⁵⁵ Morris, J et al. (2002) "At home or away? An exploration of policy and practice in the placement of disabled children at residential schools". *Children and Society*, 16, 3-16.

¹⁵⁶ Lancioni G, E et al. (1999) "Review of strategies for treating sleep problems in persons with severe or profound mental retardation or multiple handicaps", *American Journal of Mental Retardation*, 104, 170-186.

¹⁵⁷ Beresford, B (1995) *Expert opinions: a national survey of parents caring for a severely disabled child*. Bristol: Policy Press.

¹⁵⁸ Strategy Unit consultation with parents of young disabled children.

At present, family support remains patchy. Government needs to support local providers to enable family support to be provided on a more consistent basis. This report welcomes the DfES funded feasibility study into a National Centre for Early Intervention. If implemented, such a centre could be an important hub of training and evaluation of early interventions to help guide service provision for young disabled children and those with special educational needs.

The Government published the Children's NSF in September 2004, setting out the following national standard for family support for disabled children: "children and young people who are disabled or who have complex health needs receive co-ordinated, high-quality child and family-centred services which are based on assessed needs, which promote social inclusion and, where possible, which enable them and their families to live ordinary lives."

The Strategy Unit endorses this standard as a means of emphasising need for families to receive support services through multi-agency packages of care.

Family support covers a wide range of services, from basic information to specialist interventions

Early family support strengthens parental skills to meet the needs of their disabled child. 'Family support' refers to a range of interventions and provision some of which are highly specialised and some of which are basic including information provision. When delivered effectively, these interventions can help prevent families' life chances being disadvantaged, by supporting families to meet their own needs.

- **Information, peer support and counselling:** these are highly valued by parents¹⁵⁹, and can have a positive effect on stress levels¹⁶⁰. But the availability of information is variable and many parents are uncertain where to go for advice. Counselling and peer support are also valued, especially by families of children with high needs. Families say that emotional support has enabled them to better meet the needs of their children¹⁶¹.
- **Support with caring:** all parents need a break from caring sometimes. Parents of disabled children can find this difficult if family or friends are unable to help, or if there is a shortage of daycare provision for their child. But around one-third of parents with disabled children wait over

¹⁵⁹ Baine et al. (1995) "Chronic childhood illnesses: what aspects of caregiving do parents value?", *Child: Care, Health and Development*, 21, 291-304.

¹⁶⁰ Beresford, B A (1994) "Resources and strategies: how parents cope with the care of a disabled child", *Journal of Child Psychology & Psychiatry*, 35, 171-209.

¹⁶¹ Strategy Unit consultation with parents.

a year for a short break service¹⁶². And families with very young children¹⁶³, children with complex needs¹⁶⁴, “challenging” behaviour¹⁶⁵ and Autistic Spectrum Disorders¹⁶⁶, as well as those from minority ethnic communities¹⁶⁷, are less likely to have short breaks. Some families have access to domiciliary carer who comes to the family home to help care for a disabled child; however, the carer is often unable to care for any of the other children which reduces the break provided for the parents. The National Service Framework for Children highlights the importance of supporting families with disabled children. It points out that packages of care

should be responsive to the needs of the whole family including the father and siblings.

- **Sleep and behaviour programmes:** these can help families build coping strategies if their child has significant problems with sleeping or has behavioural needs. Sleep scheduling and bedtime routines can reduce sleep interruptions with benefits for both the parent and child¹⁶⁸ including improved children’s daytime behaviour, maternal sleep patterns and mental health¹⁶⁹. Behavioural programmes have been shown to address behaviour problems as well as reduce stress and disruption to family life¹⁷⁰.

¹⁶² Mencap (2004) *Breaking Point: A report on caring without a break for children and adults with severe or profound learning disabilities*.

¹⁶³ Chadwick O, Beecham J, Piroth N, Bernard S, Taylor E. (2002) *Respite Care for Children with Severe Intellectual Disability and their Families: Who Needs It? Who Receives It?* *Child and Adolescent Mental Health* 7 (2): 66-72.

¹⁶⁴ Mencap (2004).

¹⁶⁵ Heslop P., Byford S., Weatherley H. (2003) *Better Rewards: The costs and effectiveness of employing salaried support carers to reduce waiting lists for short-term care*. Shared Care Network. Bristol.

¹⁶⁶ Tarleton B, Macaulay F. (2002) *Better for the break?*, Barnardos. Basildon, Essex.

¹⁶⁷ Hatton, C., Akram, Y., Shah, R., Robertson, J. & Emerson, E. (2002). *Supporting South Asian families with a child with severe disabilities*. Institute for Health Research, Lancaster University.

¹⁶⁸ Lancioni *et al.* (1999); Wiggs, L and France, K (2000) “Behavioural treatments for sleep problems in children and adolescents with physical illness, psychological problems or intellectual disabilities”, *Sleep Medicine Reviews*, 4, 299-314; Lucas, P *et al* (2002) “Do behavioural treatments for sleep disorders in children with Down’s syndrome work?”, *Archives of Disease in Childhood*, 87, 413-414.

¹⁶⁹ Quine L (1993) *Working with parents: the management of sleep disturbance in children with learning disabilities*. In: Kiernan C (Ed) *Research to Practice? Implications of research on the challenging behaviour of people with learning disability*. BILD Publications, Kidderminster; Wiggs L & Stores G (2001) *Behavioural treatment for sleep problems in children with severe intellectual disabilities and daytime challenging behaviour: effect on mothers and fathers*. *British Journal of Health Psychology* 6, 257-269.

¹⁷⁰ Feldman and Werner (2002) “Relationships between Social Support, Stress and Mother-Child Interactions in Mothers with Intellectual Disabilities”, *Journal of Applied Research in Intellectual Disabilities*, 15: 4, 314-323.

- **Home-based learning programmes**¹⁷¹: there are a growing number including Portage, Early Bird and Lovaas. Portage aims to improve a child's development of play, communication, relationships and learning through a home visitor working with parents. Early evaluations of portage schemes in the UK indicate positive results in child development¹⁷² and families have reported high satisfaction with the service¹⁷³. Early Bird is aimed specifically at children with Autistic Spectrum Disorders.

One approach for which there is considerable evidence is the provision of a **key worker**. Families with a key worker report less isolation, higher morale and better relationships with service providers¹⁷⁴. However, less than a third of families with severely disabled children have a keyworker service¹⁷⁵. Key workers have three main aspects to their work: information, communication and care coordination¹⁷⁶. They ensure that families have a good understanding of how services work, what they are entitled to and

information about their child's needs. The keyworker also communicates between services and coordinates assessments and early intervention. Standards for key worker provision have recently been developed by the Care Coordination Network¹⁷⁷.

Effective keyworker provision can include telephone and email to complement home visits. The Early Support Programme estimates that establishing new key worker services for children with complex and multiple difficulties under three would involve an equivalent of one-and-a-half to two additional full-time equivalent staff in a local area. Families with high needs, because of severe impairment or other circumstances, should be given priority access to a keyworker. Eligibility criteria for the service should be transparent and developed in partnership with local service providers and parent support groups.

The Strategy Unit supports the roll-out of the Early Support programme stated in the Child Poverty Review 2004, subject to evaluation. It will be important that

¹⁷¹ The possible National Centre for Early Intervention could have an important role in monitoring, evaluating and disseminating information on the relative merits of different programmes.

¹⁷² See, for example, Cameron, RJ (1982) "Working Together: portage in the UK", cited in Daly et al (1985) *Portage: the importance of parents*, NFER-NELSON.

¹⁷³ Strategy Unit consultation with parents.

¹⁷⁴ Greco, V, Sloper, P and Barton K (2004) *Care coordination and key worker services for disabled children in the UK*, SPRU University of York.

¹⁷⁵ Greco, V and Sloper, P (2004) "Care coordination and key worker schemes for disabled children: results of a UK wide survey". *Child: Care, Health and Development*, 30, 13-20.

¹⁷⁶ Department for Education and Skills (2004) Professional Guidance, Early Support Programme.

¹⁷⁷ See www.york.ac.uk/inst/spru/ccnukstandards.htm.

workforce capacity is strengthened to support the dissemination of the programme materials.

**Recommendation 5.4:
Keyworkers**

From 2006, Joint Area Reviews of Children's Services should, in consultation with local authorities, consider including provision of a keyworker to families as a key performance indicator of local social care, education and health services. The indicator should be consistent with the National Service Framework recommendation on keyworking. DH and DfES to lead.

From 2006, Children's Trusts should ensure that all families have access to clear information about local services and support in both the statutory and voluntary sectors, through, for example, the Early Support Programme materials and a local website. DfES to lead.

Services can be skewed towards later intervention rather than preventative work

Social care is the main source of the family support that families with disabled children value. Local authorities develop threshold criteria to determine which disabled children's needs will be met, to allocate tight resources between competing priorities.

Box 5.4: Eligibility criteria can exclude disabled children with significant needs

In 2003, 29,000 disabled children received support from social services¹⁷⁸. One example of local authority eligibility criteria is given below:

"Of children with a physical disability, only those who are unable to walk without aids or assistance are eligible for assistance ...

The following children are not eligible for support:

- children who have a mild or moderate learning disability, where this is the only disability;
- children with ADHD, ADD, Oppositional Defiance Disorder or similar behavioural diagnosis unless this is secondary to a substantial and permanent disability;
- children with mental health difficulties unless this is secondary to a substantial and permanent disability."

Local eligibility criteria can result in a 'postcode lottery' of provision – services are provided on the basis of where people live and on individual parents' ability to lobby for provision¹⁷⁹ – rather than on an entitlement based on need.

¹⁷⁸ National Statistics (2004) "Child in Need in England: Results of a survey of activity and expenditure as reported by Local Authority Social Services' Children and Families Teams for a survey week in February 2003".

¹⁷⁹ Audit Commission (2003) Services for Disabled children: A review of services for disabled children and their families.

Social care budgets can also become skewed towards later, more intensive (and often more expensive) interventions for older children, such as residential placements for children from about nine years onwards. Costs of residential care for disabled children can range from £200 to £500 per night; and out-of-county placements for small numbers of children can dominate total social services spend on disabled children, with implications for the budget available for early intervention and younger children with other needs.

Box 5.5: County council spend on disabled children

A county council in England provides services to 729 disabled children in its area. But 40% of its disabled children's budget¹⁸⁰ is spent on 27 children in long-term residential placements. Provision for these children costs an average of £46,336 each per year.

The other 702 disabled children receive services from the remaining budget, including outreach, break holiday, portage and short term breaks. Short term residential breaks cost on average £6,082 per child per year. Holidays cost £750 per child.

Earlier intervention could enable children's needs to be met within a mainstream setting and at home with their family

It is possible that some disabled children and young people could avoid long-term institutionalisation if adequate and early preventative support was provided to them and their family. This support could include family support services such as behaviour programmes, home-based support services and adequate shared care arrangements. The Children's NSF includes standards on family support, early interventions and break provision, which are important benchmarks for this area.

The switch to early, preventative services could enable families to stay together, avoid the disadvantages of long-term residential settings and may also lower costs over the long run. This could free up resources for more preventative work with a wider group of children. More evidence is needed to investigate the extent to which early family support can contribute to less long-term residential care provision and the extent to which this meets families' and children's needs – it is vital that the well-being of the child and family is not jeopardised by this re-structuring. More research is also needed on the overall cost implications and whether transitional funding is required to support children already in residential placements while re-investing in preventative work with younger children.

¹⁸⁰ Excluding staff salaries.

Recommendation 5.5:**Early intervention****Phase one:**

By 2006, DfES, with support from DH, should identify the mechanisms by which local authorities can shift the emphasis of expenditure towards early intervention, in a way that promotes the well-being of disabled children and their families.

DfES and DH should establish:

- whether this switch of emphasis can be achieved with existing spend or whether transitional funding is required while services are restructured; and
- whether the well-being of disabled children and their families is being promoted, including follow-up studies in selected areas.

The mechanisms identified, along with examples of best practice, should be disseminated at the national level.

Phase two:

If the analysis from Phase one indicates that transitional funding is required, DfES, with support from DH, should assess the case for an 'invest-to-save' pilot to be included as part of the Spending Review 2006 bidding process. If this was to be considered worthwhile, the pilot areas would

need to have a multi-agency strategy for early and holistic family support starting in the early years, involving parents and disabled children. And the pilots would need to be fully evaluated to establish whether families' and children's overall well-being has been promoted.

Depending on the pilot outcomes, DfES, with support from DH, might then consider rolling out a national fund to provide transitional funding to re-structure services towards early family support provision for families with young disabled children.

Disabled children risk developmental delay owing to lack of specialist equipment

Specialist equipment – including community equipment, communication aids, wheelchair services and prosthetics – can be delayed and may not be adequately adapted as the child grows¹⁸¹.

Waiting for equipment can mean it does not fit the child when it does arrive, with developmental implications for the child. This is important given the increase in numbers of technology-dependent children.

In a survey of 3,000 families with a severely disabled child, 77% reported unmet needs for community equipment, to help with,

¹⁸¹ Audit Commission (2003).

¹⁸² Beresford, B (2003) *Community equipment: use and needs of disabled children and their families*, University of York.

for example, eating, going to the toilet and sleeping¹⁸². Families from minority ethnic groups, those with pre-school children and those looking after their child in the home reported greatest unmet need.

Box 5.6: Developmental implications of delays in equipment

A 3 year old child who needed a piece of equipment – an adapted toilet seat – was refused a nursery place because she was not yet toilet-trained. In this way, a delay in providing a simple piece of equipment meant this child faced longer term developmental delay and barriers to social inclusion.

Equipment should be provided to disabled children promptly based on a multi-agency assessment that occurred as soon as possible after the child's needs were identified. The DfES-sponsored Communication Aids Project (CAP) offers an interesting model. It supports school-age children facing significant speech, language and communication difficulties and operates on a referral basis, with equipment matched to individual needs following a specialist assessment. The project was recently independently evaluated, with positive results.

Children grow quickly and action should be taken to ensure equipment can be re-used and

replaced, subject to adequate maintenance.

Recommendation 5.6: Equipment

DH should assess, by 2006, whether integrated community equipment services, communication aids provision and wheelchair services are able to deliver the NSF recommendation on children's equipment, and, if not, make recommendations for improvement.

From 2006, the Joint Area Review should consider, in consultation with local authorities, using equipment services as a key performance indicator of local social care, education and health services. The indicator should be consistent with the National Service Framework recommendation on equipment. DfES and DH to lead.

Many families with disabled children live in unsuitable housing

As many as three out of four families with disabled children live in unsuitable housing¹⁸³, a higher figure than for the population in general¹⁸⁴. This means that families are put under considerable stress and may not be able to meet their child's needs – even basic needs such as playing, joining in with family life and moving around the house. Lack of suitable housing can also make families more dependent on external care and support services.

¹⁸³ Oldman, C and Beresford, B (1998) "Homes unfit for children: Housing, disabled children and their families", Bristol: Policy Press.

¹⁸⁴ Beresford, B and Oldman, C (2002) "Housing matters: National evidence relating to disabled children and their housing", Bristol: Policy Press.

This is unlikely to be cost-effective, and reduces the independence of the whole family, including the disabled child. And as a child grows beyond the early years, housing adaptations become increasingly important as, for example, lifting becomes more difficult. Both middle-income and low-income families report housing problems. Housing problems are not just an issue for children with physical impairments. Families where the child has behaviour or learning difficulties are more likely to have problems with where the house is located or safety issues within the house.

In one survey¹⁸⁵, one in ten families with severely disabled children had received some financial assistance with housing adaptations. This was typically a Disabled Facilities Grant (DFG). A third of these families also made their own contribution to the cost of the adaptations. And among families assessed as needing housing adaptations, a third had been unable to meet the contributory costs required and the adaptation had not been carried out.

Recommendation 5.7: Housing

Recommendation 4.9 in Chapter 4 should also apply to families with disabled children and/or disabled parents to ensure that these families' housing needs are met. ODPM to lead with support from DfES.

5.4 Services 'fit for purpose'

Overarching vision for services 'fit for purpose':

by 2020, early years services are capable of meeting the needs of disabled children through a trained workforce, effective joint working and a clear understanding of the needs of disabled children in their area.

Early years services need to continue developing and strengthening in order to meet the needs of young disabled children in specialist and mainstream settings. This requires a workforce with the necessary range and depth of competencies, effective joined-up working between agencies and information to enable service planning. It also requires incentives for local service providers to meet proactively the needs of disabled children.

The public sector duty to promote disability equality will require future policies to be scrutinised to ensure they promote, rather than diminish, opportunities for disabled children. The forthcoming duty means that a proactive approach will be taken to promoting equality of opportunity for disabled children and will in many situations require improved joint-working to deliver the outcomes identified in Disability Equality Schemes.

¹⁸⁵ Beresford and Oldman (2002).

The workforce needs strengthening if services are to meet disabled children's needs

The children's workforce is not fully able to meet the needs of the changing disabled children's population. There are shortages of certain professionals such as social workers and speech and language therapists. There is also a need to build up core competencies in the health and education workforce¹⁸⁶,¹⁸⁷ regarding expected child development and behaviour, and early indications of special educational needs.

Parents of disabled children report satisfaction with specialist workers such as health visitors with competencies to support disabled children¹⁸⁸. Early intervention by paediatric therapists – such as speech and language therapists – can have significant benefits for the cognitive and behavioural development of young children.

Box 5.7: Accredited nurseries in speech and language therapy

The 'I CAN' model of early years education integrates speech and language therapy within a pre-school educational setting. Two different models of integration have been evaluated¹⁸⁹ for

children with severe and specific speech and language difficulties. In both cases, parental involvement is important and the aim is to support the children's inclusion in mainstream provision at the end of the intervention.

The I CAN children improved in comparison with peers attending routine NHS provision, in their productive vocabulary, language comprehension and adaptive and social behaviour. The children were less disruptive as a result of the intervention. In addition, the I CAN provision was found to be relatively cost-efficient. This model is promising in terms of early intervention and inclusion of disabled children and those with SEN in mainstream provision.

It will be important to plan strategically the competencies and working models required in the early years workforce to use people and resources more effectively. For example, consideration of therapy provided in group settings as well as individually; a "consultative" model of specialists providing specialist input into mainstream services rather than dealing exclusively with individual cases; and a local, floating resource of specialist child health

¹⁸⁶ See recommendation in Department of Health (2004) The Chief Nursing Officer's review of the nursing, midwifery and health visiting contribution to vulnerable children and young people.

¹⁸⁷ See recommendation in DfES (2004) Removing the barriers to achievement: The Government's strategy for SEN.

¹⁸⁸ Strategy Unit consultation with parents.

¹⁸⁹ Law, Dockrell et al (2001) The I CAN Early Years Evaluation Project, City University and the Institute of Education.

visitors who can be allocated to families with additional needs.

Every Child Matters has set out a series of workforce reforms to deliver the vision for children's services. A Children's Workforce Unit has been established to develop a pay and workforce strategy for the children's workforce. There will also be a Sector Skills Council for Social Care, Children and Young People to bring together those working with children and young people in fields related to social care.

In England, the DfES and DH are supporting the establishment of a Children's Workforce Development Council to develop qualification and training frameworks. The Council will work with employers, training and education providers to supply training for the children's workforce to improve capacity and workforce quality.

These reforms could also be linked to the possible National Centre for Early Intervention. The centre could be a national centre for accredited training in early intervention.

Recommendation 5.8: Workforce

DfES, with DH, should ensure that the children's workforce is capable of fully meeting the needs of disabled children, primarily through working with the Children's Workforce Development Council. This work should take full account of the changing profile of

disabled children, and should include the full spectrum of professionals in contact with disabled children including primary and secondary healthcare professionals. Incorporate into current work.

Service providers still do not work together effectively or plan strategically

There remains a lack of joined-up working and strategic planning on the ground, leading to gaps in service and information provision – particularly between health, social services and education departments¹⁹⁰.

This lack of strategic planning and working means that services can fail to meet the changing needs of the disabled children's population. There is significant unmet need for key services by families from minority ethnic communities and by families with children with complex needs. Poor cross-agency working can also create artificial barriers, such as provision of transport only between school and home restricting access to leisure.

Multiple assessments remain the norm, although some areas have made progress on developing shared assessment procedures. Overall, the lack of multi-agency working and planning remains a barrier to meeting the needs of disabled children and their families.

¹⁹⁰ See, for example, Audit Commission (2003).

Some Children's Trusts pathfinders are focusing on services for disabled children. This is promising, although it is too soon to tell what the impacts are for families with disabled children. In addition, the public sector duty to promote disability equality will require improved joint working and strategic planning to meet outcomes set out in Disability Equality Schemes.

Box 5.8: Case study of Children's Trust pathfinder

Nottinghamshire Children's Trust pilot is focusing on disabled children and young people and their families and carers. It is planning to develop an Integrated Pathway that is structured around the milestones that occur during the journey a child and family makes through local services. The milestones are information services, referral, assessment, service planning, service delivery and service review. In addition, Mansfield has an 'invest to save' funded multi-disciplinary team for disabled children.

The Common Assessment Framework is aiming to establish a core set of information that can be shared between agencies. It will be important that the Framework meets the specific needs of disabled children because virtually all disabled children are in contact with more than one agency.

The Strategy Unit welcomes the provision in the Children Bill for Joint Area Reviews of children's services to report on the extent to which local services work together to improve the well-being of children and young people.

**Recommendation 5.9:
Children's Trusts**

Local authorities, PCTs and, from their inception, Children's Trusts should work together and with their partners to strategically commission services for disabled children, including early years and the transition into school, with a view to meeting the NSF standards. This process should take full account of the needs of all disabled children in their area, including those who do not meet current eligibility criteria. DfES and DH to lead.

There need to be robust ways of ensuring standards of service provision improve over time

Apart from family support in social care performance indicators, there are no national public sector targets on provision or outcome for disabled children. This means that there is no incentive for local service providers to prioritise services for disabled children.

However, the Disability Equality Schemes required under the new public sector duty will require public authorities to assess the extent to which their services meet the needs of disabled people. This is likely

to include measures of whether disabled people and children can access services and the extent to which services contribute towards the outcomes required.

There are also some Local Public Service Agreements between local authorities and central government that are focused on disabled children (see Box 5.9 below). A local Public Service Agreement is a local authority's commitment to central government to deliver specific improvements in performance. The agreement also reflects government's commitment to reward and support these improvements. These are promising mechanisms for improving outcomes for disabled children in their families.

Box 5.9: Examples of Local Public Service Agreement targets focusing on disabled children

Halton Borough Council
"Providing children with disabilities with increased choice to a range of short-term breaks".

Northumberland County Council
"Providing children with disabilities with increased choice and access to short break overnight care".

West Berkshire Council
"To increase the number of children with Special Educational Needs/Disability included in specialist and mainstream setting".

Cambridgeshire County Council
"To improve parent satisfaction with services for children with disabilities/special educational needs".

There are also proposed arrangements for Joint Area Reviews of children's services to involve a number of inspectorates including Ofsted, the Healthcare Commission, the Commission for Social Care Inspection and the Audit Commission. Joint Area Reviews will report on the well-being of all children and young people in a local area. They will cover universal, preventative and specialist services and particular attention will be given to joint action by local services on behalf of those groups of children and young people who are vulnerable to poor outcomes. Disabled children will be covered in detail in every review. This is a welcome proposal that should give an incentive to service deliverers to meet the needs of disabled children and young people in their area.

The relationship between the Joint Area Review and the Comprehensive Performance Assessment will be important as a driver for overall improvement in performance with respect to disabled children and young people, particularly if it identifies the effectiveness of Disability Equality Schemes in improving outcomes for disabled children. The Disability Discrimination Bill public sector duty will cover

inspection and audit bodies so they will be expected to promote disability equality through their work.

**Recommendation 5.10:
Joint Area Reviews**

The Strategy Unit supports the proposed inclusion of disabled children and young people as a specific theme within the Joint Area Reviews of children's services.

DfES and DH, from 2006 onwards, to consider how performance in disabled children's services can be reflected in the Joint Area Reviews of children's services and the annual Comprehensive Performance Assessment rating.

There is insufficient data on disabled children

Local information on the needs of families with disabled children – including age, ethnicity, complexity of needs – is not always shared effectively across agencies. Often only information about families who meet social services eligibility criteria are collected rather than the wider population of disabled children. This makes it difficult for local services to plan and commission effectively for disabled children's needs¹⁹¹. Assessing impairment in the under-fives can be difficult because some conditions are challenging to diagnose when the child is very young¹⁹². However, the earlier that information is collected about the additional needs of

children, the better services can be designed to meet their needs. The new duty on public bodies to promote disability equality will require sufficient evidence gathering to effectively inform both action plans and measure outcomes.

There are two levels of information that can be used to plan services and understand the changing needs of children. The first is a basic level of information on numbers, age, ethnicity and impairment. The second is a more detailed level of information, likely to be provided by families themselves, of the family's needs, current services they use and a record of unmet need.

Box 5.10: Case study of the Compass database

Brighton and Hove City Council and local health services fund The Compass as the area's official disability register. The database is managed by a voluntary sector provider – aMAZE – which also offers advice and support to families with disabled children. The database is voluntary with an incentive of a free leisure pass to families who register. The information is used to strategically plan services in the area that take account of the profile of the local children's population and their additional needs. Families who do not meet social services eligibility criteria are also able to register.

¹⁹¹ See Audit Commission (2003).

¹⁹² Gordon, D., Parker, R *et al* (2000) *Disabled Children in Britain: a re-analysis of the OPCS disability surveys*. London: The Stationery Office.

Initiatives are being planned to improve data on children. Local authorities are already required under the Children Act 1989 to establish a register of disabled children. Some have used innovative ways of collecting data that provide a multi-agency database that can be used to strategically plan services (see Box 5.10). But many have found it difficult to maintain a database. The introduction of the new Child Health Promotion Programme, as part of the NSF on Children's Services, offers new opportunities to ensure that disabled children's physical, emotional and social development is regularly assessed and provision made that is appropriate to their needs.

The Children's Bill enables the Secretary of State, subject to "affirmative resolution" in Parliament, to require databases with basic information on all children to be established. These could be at a local, regional or national level. But it remains uncertain whether information would be collected about additional needs of disabled children that would enable services to be planned effectively.

Recommendation 5.11: Data collection and information sharing

DfES and DH, 2005 onwards, should work with Local Authorities, PCTs and Children's Trusts to look at ways to coordinate basic data on the number and needs of disabled children in the local area within existing resources. The data should include a full audit of the needs of children in the area, irrespective of whether children meet current eligibility criteria.

DfES and DH should ensure that information on the situation and needs of disabled children are effectively included in the design and implementation of the databases resulting from the Children Act 2004. The databases to be designed to enable national statistics on disabled children to be compiled readily. Incorporate into current work.

DfES and DH should ensure that the Common Assessment Framework fully takes the needs of disabled children and young people into account in its design. Incorporate into current work.

Chaper 6: Transition to adulthood

Summary

The benefits of effective early years intervention will be lost if disabled young people's transition through childhood and into adulthood is not managed effectively. There are particular barriers for two groups:

- those with the highest level of need who may be offered inappropriate segregated adult services (or in some cases be offered no support at all because they are seen as 'too disabled' for local provision); and
- those with less significant needs but little entitlement to additional support.

There are three key ingredients needed for effective support for disabled young people, to ensure that they enter adulthood able to participate and be included.

- Planning for transition focused on individual needs.
- Continuous service provision.
- Access to a more transparent and appropriate menu of opportunities and choices.

Over time, individualised budgets will allow seamless transition from childhood to adult services, providing disabled young people and their families with choice and empowerment.

In the shorter term:

- children's and adult services should overlap to improve **continuity** and remove the "cliff-edge" in provision experienced by many disabled young people;
- the role of **families** needs to be recognised and supported in a way that empowers disabled young people and their parents;

- **personalisation** in planning will require increased access to advocacy and information; person centred planning approaches to be used widely; and a Connexions service committed and equipped to support disabled young people; and
- **opportunities** for disabled young people to improve their life chances should be provided through inclusion in further education and employment preparation, and accessible mainstream leisure and cultural activities and youth services.

Section 6.1 of this chapter outlines the current situation faced by disabled young people at the transition into adulthood. Sections 6.2, 6.3, 6.4, and 6.5 propose changes to improve continuity, family support, personalisation, and future opportunities respectively.

6.1 What is the current situation?

Becoming an adult and moving into adult services

Becoming an adult affects many aspects of young people's lives

Being on the cusp of adulthood should be an exciting time. Leaving compulsory schooling is accompanied by decisions about future education and employment, and there are changes in family life, social networks and emerging sexuality to contend with. Becoming an adult is also about increased independence and a new orientation in leisure and cultural activities, housing situation, and health care needs¹⁹³.

Disabled young people face additional barriers that affect their move into adulthood and into adult services

Disabled young people hope for the same things as other young people; to travel, get a good job, start a family, and live independently. They want a voice, a leisure and social life, and to be involved as active, valued citizens¹⁹⁴. However they also face disabling social, attitudinal and environmental barriers, that can cause disruption and anxiety, and delay or even prevent the achievement of independent living and social inclusion. The complexity of a transfer from services provided to children to services provided to adults also affects many young people. Their relationship with their family may also be more complex, particularly where parents have an on-going role in providing personal assistance and where disability-related allowances or benefits are an important contribution to the household income.

¹⁹³ SCARE Research Briefing 04: *Transition of Young People with Physical Disabilities or Chronic Illness from Children's to Adult's Services*.

¹⁹⁴ NOP (2003) A survey of the views and experiences of young disabled people in Great Britain, conducted by NOP on behalf of the Disability Rights Commission, DRC: London; Morris (1999) *Hurting into a Void* JRF: York; and Heslop, P et al. (2002) *Bridging the Divide at Transition: What happens for young people with learning difficulties and their families?* BILD: Glasgow.

Many disabled young people have experienced discrimination and have low expectations of their future prospects

Disabled people at age 16 and 26 are less satisfied with their lives and have lower subjective well-being than non-disabled people of the same age¹⁹⁵. Many feel that they are not safeguarded a right to be part of the community, and to have choices¹⁹⁶.

Box 6.1: What disabled young people say of their experiences in ...

School: 20% of disabled young people said that they were discouraged from taking GCSEs because of their impairment, with 12% discouraged from taking A/AS levels and 12% discouraged from taking vocational qualifications.

Further or higher education: 60% of disabled young people who did not enter further or higher education said they believed they would not have got the support they needed.

The labour market: 86% felt it was harder for disabled people to find work, and 30% expected, by age 30, to be earning less than other people their age.

Leisure and social activities: 64% would have liked to play sport¹⁹⁷ but found it difficult or impossible and 32% said that they had limited access to social activities because of their additional needs¹⁹⁸.

Experiences in young adulthood are a significant determinant of future life chances

Disabled people often do not achieve the qualifications that they could at school owing to a range of factors – including negative experiences of schooling, low expectations from teachers, special schools lacking an academic orientation, and a lack of education provision during hospital and other absences. A recent Ofsted report on SEN and disability found that most mainstream schools are now committed to meeting SEN as a result of the Government's revised inclusion framework¹⁹⁹. However this inclusion framework continues to have little impact on the proportion of pupils with SEN in mainstream schools or on the range of needs for which mainstream schools cater. The admission to mainstream schools of pupils with behavioural difficulties was found to be the hardest test of the inclusion framework. This is the group

¹⁹⁵ Analysis excludes those with learning impairments. Burchardt, T., (unpublished paper, work in progress) *Fate and fortune: outcomes for young people at age 26 according to disability status at 16*. Based on data from the 1970 Cohort Study.

¹⁹⁶ Morris, J. (2001) 'Social exclusion and young people with high levels of support needs,' *Journal of Critical Social Policy* Vol 21(2) pp.161-183.

¹⁹⁷ Also see Sport England (2001) *Disability Survey: Young People with a Disability and Sport* London.

¹⁹⁸ NOP (2003).

¹⁹⁹ Ofsted (2004) *Special educational needs and disability: Towards inclusive schools*. Ofsted.

particularly likely to fall out of education at age 16.

Reducing the proportion of young people not in education, employment or training (NEET) has been identified as a government priority, and is expressed in several key DfES Public Service Agreements and long term targets²⁰⁰. By the age of 21, people who are NEET are more likely to be unqualified, untrained, unemployed, earning less if employed, a parent and experiencing poor mental health²⁰¹. As discussed in Chapter 2, disabled young people are considerably more likely than non-disabled people to be NEET, particularly from age 19 when many will first transfer out of special school.

Becoming an adult is a long journey, but the legal transfer from child to adult services occurs when people are aged 16–19

Transition into adulthood varies, but can be a gradual shift towards independence spanning ages 13 to 30 or later. The legal transitions between child and adult services, however, occur between ages 16 and 19. For example, young people

usually move from child to adult health services at 16; from child to adult social services at 18; and from school-based education to further or higher education at 19. About 7% of the British population aged 16–19 are covered by the DDA – 0.2 million people – although many of these will not meet eligibility criteria for various services, particularly adult social care²⁰². Estimates vary with what survey data is used, ranging from 6%–10% of men and 8%–12% of women aged 16–24 reporting a LLSI²⁰³. There is evidence that prevalence of impairment among young adults is increasing.

There is great variation in impairment profile, but the evidence base for this group is lacking

The nature of young people's impairment is highly varied and the profile is changing. Increasing numbers of children with complex needs are both surviving into adulthood, and experiencing increased life expectancy as an adult²⁰⁴. Significant increases in the diagnosis of ASD and mental health problems present particular issues for adult services to respond to²⁰⁵.

²⁰⁰ Godfrey, C. et. al (1999) *Estimating the Costs of Being "Not in Education, Employment or Training" at Age 16-18* DfES Research Report RR346.

²⁰¹ HMT, DWP, DfES (2004) *Supporting young people to achieve: towards a new deal for skills*. TSO: London. Also discussed in Social Exclusion Unit (1999) *Bridging the Gap: New Opportunities for 16-18 year olds Not in Education, Employment or Training*, London: TSO.

²⁰² Family Resources Survey 2002/3.

²⁰³ General Household Survey (2001); Health Survey for England (2002).

²⁰⁴ Glendinning C. et al. (2001) 'Technology-dependent children in the community; definitions, numbers and costs' *Child: Care, Health and Development*, 27(4) 321-34. Betz, C.L. (1999) 'Adolescents with Chronic Conditions: Linkages to Adult Service Systems.' *Paediatric Nursing* 25(5): 473-476

²⁰⁵ This is discussed in more detail in chapters 2 and 5.

Significant gaps persist in the evidence at both the national and local level, and there is variation in the definitions used²⁰⁶. Large-scale longitudinal data sources that follow-up a large and representative sample of disabled young people who transfer from child to adult services need to be developed. Little research has diagnosed what models of intervention work most effectively, for whom, and in what circumstances²⁰⁷, and few cost benefit analyses of the impact of interventions with disabled young people have been carried out. There has also been relatively little work with a holistic view of transition, with young people with the most complex needs and/or from BME groups, or which focuses on the impact of the family on disabled young people's experience of the transition towards adulthood and independence²⁰⁸.

The service and policy context for disabled young people and their families

Three in four disabled young people believe they are under-represented in national policy and that the

*Government is not interested in their needs*²⁰⁹.

While there has been progress in promoting disabled young people's opportunities in recent years²¹⁰, enormous disadvantage remains. Recent years have witnessed a significant focus in government policy on tackling social exclusion. However, when disabled young people were asked about what 'social exclusion' meant to them the issues they raised were somewhat different to those that government policy has generally focused on and included:

- not being consulted or listened to;
- having no friends or finding it difficult to maintain friendships; and
- being made to feel like a burden, with no contribution to make²¹¹.

*There has already been a policy focus on transition; there is now a need to address implementation*²¹².

²⁰⁶ This chapter considers disabled people and those with SEN, while recognising that these two groups do not entirely overlap. Young people identified as having special educational needs (SEN) find that the definition (and any Statement of SEN) no longer holds currency in adult services.

²⁰⁷ E.g. there is little research specifically on the role of a 'transition worker'.

²⁰⁸ E.g. Heslop (2002).

²⁰⁹ NOP (2003).

²¹⁰ E.g. duties introduced through SENDA, which improve the profile and inclusion of disabled young people in education, and the health and social care standards in the Children's NSF.

²¹¹ Morris, J. (2001).

²¹² This was emphasised by the Disabled Children Sub-Committee of the Association of Directors of Social Services and with managers and practitioners working in transition, in consultations with the Strategy Unit.

Box 6.2: Summary of recent policy and legislation addressing transition

Integrated models of working and transition protocols have been developed, including:

- **Connexions Partnerships;**
- **SEN Regional Partnerships;**
- **transition champions on Learning Disability Partnership Boards;**
- **a Transition Working Group, co-ordinated by DfES; and Framework for Inspection of Children's Services.**

Personalisation of services has been highlighted widely, including in:

- **the Valuing People Strategy²¹³;**
- **the SEN Strategy, 'Removing Barriers to Achievement'; and**
- **Additional Support for Learning (Scotland) Act²¹⁴.**

Transition is on the agenda in health, social care and education, e.g. in:

- **National Service Frameworks (NSFs)²¹⁵;**
- **Children's Trust Pathfinders** including disabled people up to age 25;
- **Direct Payments** extended to 16 and 17 year olds and family carers; and
- **range of education programmes** and legislation, such as the Every Child Matters green paper, Learning and Skills Act (2000); SENDA (2001); and the Extended Schools and Widening Participation programmes. Some 14–19 pathfinders are looking at the move into supported employment. The Beattie report, *Implementing Inclusiveness Realising Potential*, has had a major influence on transition practice in Scotland.

Much of the wider policy concerning children and young people has failed to include those with impairments

Despite the increased focus on transition, there has been relatively little mention of mainstreaming the requirements of disabled young people²¹⁶. It will be important that

²¹³ Valuing People have pilots in five local authorities, developing links between person-centred planning and transition.

²¹⁴ This Act comes into force in Scotland towards the end of 2005, when it will place certain duties on education authorities for sharing information with other agencies.

²¹⁵ The Welsh and English NSFs for children; the NSF for long-term conditions; and the English NSF for mental health (which includes early intervention pilots with teenagers).

²¹⁶ E.g. the Education five-Year Strategy, National Skills Strategy, Teenage Pregnancy Strategy, and the Children's Bill.

this omission is addressed as future policy is developed²¹⁷. The public sector duty – discussed earlier in this report – will have a role here.

What currently happens at transition

Young people with less significant impairments are at risk of leaving school at 16 without the skills to compete in the labour market

Most disabled young people have contact with at least some types of services, although the extent and nature of contact varies enormously. Young people with less severe impairments (such as those with mild or moderate learning difficulties, or communication or mental health problems) often have little or no contact with services such as social care as they are not deemed eligible, particularly once they are adult²¹⁸. The lack of support that they receive on leaving compulsory education has been raised as a factor in the high proportion of people with less severe impairments coming into contact with the Youth Justice System, experiencing homelessness, teenage pregnancy, drug and alcohol misuse and becoming NEET²¹⁹.

Those with a higher level of support need often experience multiple assessments and service contacts, and end up in segregated provision

In contrast, young people with the most significant impairments tend to experience a delayed transition at 19, on leaving special school. They and their families can experience difficulty co-ordinating the numerous services with which they come into contact. This process becomes more intrusive and complex as the young person approaches adulthood, when changes in entitlement result from change in age and not need, and there are multiple, separate, but overlapping assessment pathways. There are often delays in getting adult services set-up and provision is likely to be age-inappropriate. They may end up in segregated, sometimes costly residential, provision, due to the lack of alternative opportunities²²⁰.

6.2 Continuity

Overarching vision for delivering continuity in service provision: by 2015, all disabled young people and their families will experience continuity and co-ordination in the services that they receive, as both children and adults. This will result

²¹⁸ A survey following up young people with mild learning disabilities in Aberdeen found that by age 22 just 20% were receiving specialist services, although 73% had problems with daily living. (Richardson, S. and Koller, H. (1996) *Twenty-Two Years: Causes and Consequences of Mental Retardation*, Cambridge: Harvard University Press.)

²¹⁹ Myers, F (2003) *On the Borderline? People with learning disabilities and/or ASD in secure, forensic and other specialist settings*, Scottish Office CRU: Edinburgh; Hawkins C and Gilbert H *Dual diagnosis toolkit: Mental health and substance misuse*, Turning Point and Rethink.

²²⁰ See the SU supplementary report, 'The most marginalized groups', published on www.strategy.gov.uk.

from their own increased control and empowerment (through mechanisms such as person-centred planning and Individualised budgets) and through the improved communication and sharing of information, responsibility and joined up budgets across agencies and between child and adult services.

Young people experience a lack of continuity in service provision at transition

A key problem leading to lack of continuity in provision across transition stems from the different entitlement criteria and definitions between child and adult services. A number of other barriers also contribute to the persistence of fragmented service delivery. These include:

- poor communication, tracking, and sharing of individual level data between agencies;
- a lack of local and regional data to inform planning;
- cultural and professional barriers between different service providers, and restricted perceptions of areas of responsibility;
- separate funding streams and targets; and
- significant regional variation in performance and a lack of dissemination of good practice.

Box 6.3: Case study of the barriers to integrated multi-agency working:

Development work had been on-going in one local authority to pilot an integrated transition team, involving transition workers resourced from a pooled budget. Despite agreement that the model was right, the pilot was suspended due to a failure to agree levels of budget contribution. This was compounded by adult social services being made up of multiple budgets²²¹.

There is some evidence on what works in integrating child and adult services

The achievement of effective person-centred planning should smooth young people's transition between services. There are examples of good local practice in developing models of integrated working between agencies and services across transition – models range from transition teams, through authority-wide transition training to development of information-sharing systems relevant to disabled young people at transition. Centrally held 'process maps' – detailing how and where staff interface in supporting transition – are present in some, but not all, local authorities. As part of the SEN strategy Removing Barriers to Achievement, DfES is considering producing a Practice Development Toolkit to evaluate and disseminate

²²¹ Involving health on multi-agency boards and in the pooling of budgets was also cited by various professionals as problematic due to the fragmentation of Health Authorities into smaller Primary Care Trusts (Strategy Unit consultation with transition professionals).

best practice models to all those working with young people on transition planning, including the Transition Information Network and the SEN Regional Partnerships²²².

Box 6.4: Case study of integrated working at transition

In Wiltshire, panel meetings involve Child Health and Disability Teams, adult social services and Connexions to identify all young people with SEN who are likely to need support beyond school-leaving age, and to make sure that they do not fall through the net²²³.

Local Area Agreements are discussed in Chapter 4 are one model for the cross-agency commissioning and delivery of provision. Whatever model is used, the remit will include increasing the integration of child and adult services.

Children's Trusts are being established with the remit of bringing integration and coherence to the commissioning and local strategic planning of children's services. It is essential that agencies work together to address transition and link with adult services,

including adult health provision and leisure and cultural activities. The Children Act enables Children's Trusts to focus on relevant disabled young people up to age 25, including those with complex health and social care needs for whom the transfer to appropriate adult provision has not been completed. This is already happening in some Children's Trust pathfinder areas, such as Bolton. Such an approach is central to a key issue raised in recent consultations with parents and providers around the extended time-scale of transition. Connexions have a remit to include disabled young people up to the age of 25 who are not ready to fully access adult provision, and it will be essential that the Connexions Service, as proposed in Recommendation 6.7, is able to fulfil this remit²²⁴.

**Recommendation 6.1:
Young people and their families
need to experience continuity
in delivery from child and
adult services and from
different agencies**

- Short term: Within existing budgets, DfES should identify, by 2006, different models

²²² New guidance, called Partnership Matters, has been drawn up by the Scottish Executive for colleges, social work, and health on working collaboratively to support students with additional needs in mainstream FE.

²²³ Robinson, C (unpublished).

²²⁴ Connexions Partnerships have a remit to arrange with the local Learning and Skills Council and ES a review for young people with LDD ("Learning Difficulty and Disability") in their 19th year, to agree arrangements for appropriate transition from the support provided by the Connexions Service, while ensuring continuity. Where a young person is not ready to use the adult guidance services of the LSC or ES, Connexions Partnerships should continue to support that young person, with the overall aim of helping the client make use of the adult systems that have been set up to reduce dependency on the Connexions Service. These arrangements will not extend beyond an individual's 25th birthday.

of multi-agency transition co-ordination and disseminate effective practice through existing or developing mechanisms, such the Transition Information Network (TIN) or the proposed practice development toolkit.

- Medium term: DfES should, from 2005 onwards, encourage Children's Trusts that are planning, commissioning and delivering services to young people over 16, to work with young disabled people for whom the transfer to appropriate adult provision has not been completed, up to the age of 25.
- The development of models of Individual budgets, described in Chapter 4, should, in principle, enable a more integrated response to the needs of disabled young people. Pilots should be developed to assess the specific issues that will need to be overcome if individualised budgets are to be used to cover the transition period, given the changes that occur at this time in the sources and levels of funding.

Young people are often excluded from programmes that extend self-directed support to adults

There are fixed ages at which young people are expected to transfer from child to adult social care provision and health care provision.

It is often not until they are eligible for adult services that they may be offered opportunities to become involved in new programmes introduced to extend self-directed control. Young people will need particular support to take part in such programmes – many will previously have had little opportunity to direct the nature of their support services.

Young people's health often declines at transition, an issue noted in the Children's NSF standard on transition. This can stem from a loss of health services previously accessed through school, and there being no single contact to which a paediatrician can hand over. Adolescence is also a time when young people with complex health care needs may be less likely to comply with treatment²²⁵. For these reasons early access to programmes such as the Expert Patient Programme could be key.

What works in extending adult programmes to younger people

The Children's NSF and the NSF for Long Term Conditions both highlight the need for flexibility in age of transfer, and that this should be triggered by young people's need rather than their age. The Children's NSF also recommends that Primary Care Trusts ensure children and young people have the opportunity to become Expert Patients and to participate in an Expert Patient Programme. Work is beginning on this, but needs to be developed

²²⁵ Ahmad, W (2001) *Disability, Ethnicity and Young People* JRF: TPP; Morris (1999).

further with particular attention given to encouraging recruitment²²⁶.

The Integrated Community Equipment Services (ICES) initiatives have had some success in improving the speed and efficiency with which older adults in England have received health and social care equipment²²⁷. ICES national guidance states that seamless equipment services “have an important role to play” in making the move to adult life a time of opportunity for disabled young people. While young people are included within the ICES remit in theory, this has not always been the case in practice.

Box 6.5: Case study of local partnership working extending ICES to disabled young people

The London South Learning and Skills Council (LSC) has asked the South London Learning Partnership to provide a network to facilitate agreement and establish protocols between the LSC, Further Education colleges, adult community colleges and the ICES in South London²²⁸.

In the longer term, the shift to Individual Budgets and the key role of local user-led advice, information and advocacy services proposed within Chapter 4, will include young

people in developing control over their provision. This will include retention of equipment across child to adult services where appropriate, and inclusion of young people – and their family and/or circle of support where appropriate – in the planning of their self-directed support. DfES, with its lead on children’s services, will contribute to the development of this system.

Box 6.6: Case study of enabling young people to self direct their support

Youth PASS (the Youth Personal Assistance Support Scheme) was set up by the West of England Centre for Inclusive Living (WECIL) to ‘promote independence, equality and inclusion through the provision of personal assistance to young disabled people’. It is based on the belief that young disabled people should have the same rights as disabled adults to exercise choice and control over their lives. The scheme aims to support young people in learning to make choices about how they are assisted and how to manage that assistance in the way that best meets their additional needs²²⁹.

²²⁶ There are reports about the Children’s EPP Pilot that there has not yet been a course delivered to the under 18 group, due to difficulties with recruitment

²²⁷ Audit Commission *Fully Equipped* follow-up report.

²²⁸ Davis, S (2004) ‘Integrating Community Equipment Services’ *The Skill Journal*, Issue 79.

²²⁹ Jade, R (2002) *Creating Independence and Inclusion: Youth Personal Assistance Support Scheme – Good Practice Guidelines* WECIL and the NYA. Also see Cramp and Duffy (2003) *Support Delivery Making in Practice Valuing People*.

**Recommendation 6.2:
Adult programmes that extend
self-directed control should
include young people when they
are ready, not at a fixed age**

- Short term: DH should collate and disseminate good practice examples to PCTs, by 2006, on including children and young people in the Expert Patient Programme, drawing on small-scale evaluation work currently underway.
- DH should work with the Audit Commission/Health Care Commission, by 2006, to investigate how ICES initiatives can ensure that they are including children and young people.
- Medium term: Each local authority should make sure in their strategic planning that there is support for young people developing individual budget plans and learning to manage personal assistance and direct payments. One model would be for this to be delivered by the user-led advice, information and advocacy service that Chapter 4, recommendation 4.3, proposes should be available in each authority area.

Universal provision often fails to meet disabled young people's needs

As highlighted in other chapters, new mainstream programmes are often piloted without the appropriate data being collected to enable assessment of how well they meet the needs of disabled people. The proposed new duty on public bodies to promote disability equality will require bodies covered by the specific duty to gather evidence sufficient to inform their action plans and Disability Equality Scheme.

There is currently a lack of longitudinal and cost-benefit research that includes sufficient sample and/or appropriate topic coverage to provide evidence of what works in meeting the needs of disabled young people. Inspections tend to focus either on children's services or on adult services²³⁰, and some inspection agencies lack the appropriate skills or remit to evaluate the links between agencies that are crucial to how young disabled people experience those services. It is also problematic to develop an outcome (rather than process) related performance indicator for transition, due to the multiple inputs and the time delay involved.

Various PSA targets have also failed as an incentive to focus on disabled young people. For example the emphasis on increasing the proportion of students achieving a level 2 qualification may lead schools and colleges to prioritise

²³⁰ Apart from the transition into adulthood inspection carried out in 1995 by the Social Services Inspectorate.

those nearest to achieving level 2, to the detriment of many of those with learning difficulties or complex health needs. Likewise the target on the NEET group focuses on those aged 16–18, when many disabled young people only become NEET on leaving special school at age 19.

There is some evidence on what works in leveraging universal provision to meet disabled people's needs

DWP currently has a feasibility study underway examining how information can be gathered most effectively, and exploring whether it is viable to collect this sort of information on children and young people. This feasibility work includes considering the development of a longitudinal survey.

It is encouraging that the proposals for Joint Area Reviews of children's services have highlighted the need to ensure that provision aimed at disabled children and young people are included. They are also considering the development of a case study approach to inspection, which could enable transition outcomes to be assessed. It will be essential that Joint Area Reviews include services provided for relevant young people aged up to 25.

Future PSA targets need to focus on improving the performance and participation of all young people, not just those closest to a particular level. Local PSA targets also provide

a vehicle for local development of targets which promote more inclusive practice.

Box 6.7: Case study of the use of a local PSA target

Lancashire County Council has agreed a local PSA target to improve youth participation and involvement for all young people, and highlighted within that the need to increase access to leisure activities among disabled 13-to-16-year-olds.

Recommendation 6.3: Assessments of how well 'universal' services meet the needs of disabled young people and their families

- All government departments should ensure that the evaluation of new models of service delivery (such as Extended Schools and Children's Trusts) address how well they meet the needs of disabled children, young people and their families and that this evaluation is built into their Disability Equality Scheme.²³¹
- The DRC should produce specific guidance on evidence gathering in relation to the proposed public sector duty, which addresses the need for an increased evidence base in relation to young people.

²³¹ E.g. 'Beyond 2004 – A DCMS Framework for Action on Disability' states that "all DCMS policies and projects to be assessed against the Disability Framework and the DDA."

- DWP should ensure that any new approaches to collecting long-term information on disabled people gives some priority to including a sufficient sample of children and young people, to enable the impact of the changing quality and quantity of service contact at transition to be assessed. 2006/7 and on-going.
- OFSTED, with other inspectorates, should ensure that Joint Area Reviews, from when they are first implemented, assess services provided to disabled young people up to the age of 25. The Healthcare Commission should conduct regular thematic inspections focusing on disability and transition.
- DfES should identify options by 2006 for the development of transition performance indicators that local authorities and agencies can use to audit their own transition arrangements. The production of these indicators will include DH and DCMS.
- DfES should assess the effectiveness of PSA targets on level 2 and NEET rates in improving overall performance, including the performance of disabled young people.

6.3 Family support that bridges transition

Overarching vision for delivering support to families:

by 2015, everyone with parental responsibility for a disabled young person will have access to the right support to enable them to cope, to enjoy being a parent, and to participate in the labour market if they choose. This need will be met in a way that empowers both parents and young people, and which treats disabled young people as having the same aspirations as other young people: to have choices, friends, and an appropriate leisure and social life.

Families with disabled children often lose support as their child becomes an adult

Families with a disabled young person have high levels of unmet need.

A survey of parents of disabled children found the highest levels of unmet need among those whose children were older²³³.

The impact of unsuitable housing, for example, increases with age²³⁴. In a comparison of six EU countries, families with a disabled young person in the UK were found to be the least satisfied with the practical and financial support they received²³⁵.

²³² It is difficult to develop outcome measures by which to assess transition arrangements, due to complexity of inputs and the time delay before outcomes, which is why inspection tools do not currently cover this. Rowland-Crosby, N (unpublished) Transition – A Checklist (England) provides a useful process based list of measures.

²³³ Beresford B (1995) *Expert Opinions: A National Survey of Parents Caring for a Severely Disabled Child*. Policy Press, Bristol

²³⁴ Due to lifting the young person if they have mobility needs and need for more space. See discussion in Chapter 4 on DFG.

²³⁵ Russell (2004 – forthcoming)

Disabled young people tend to remain in the familial home longer into their adult life than their non-disabled peers²³⁶, a pattern that is likely to increase with the welcome shift towards community care²³⁷. Parents often continue to be a primary carer long after their 'child' has turned 19, and beyond entitlement to parental leave²³⁸.

There are additional barriers for families from Black and Minority Ethnic (BME) groups, as some service providers assume that they will provide more assistance than white families. One study found 70% of South Asian family carers of children and adolescents with intellectual disabilities scored above a threshold for psychological distress, compared with 47% of family carers overall²³⁹.

There is a lack of accessible leisure opportunities

Parents need a break from their children sometimes, and children need a break from their parents. For most young people this is achieved through a range of social and leisure activities, such as 'hanging out' with friends,

travelling, youth clubs, and trips to the cinema, a leisure centre or the pub. Currently these options are often inaccessible to those with the most significant impairments, contributing to their becoming socially excluded, their families being unable to cope, and increasing the likelihood of their moving unnecessarily into costly residential provision, often far from their family and local community. While the extension of Direct Payments to carers and to 16-and 17-year-olds and the new availability of vouchers for 'short term breaks' are welcome²⁴⁰, their impact can be limited by the lack of appropriate leisure provision available for purchase.

The overall take-up of 'short breaks' by families from BME groups has not been improving. There is significant unmet need and a disproportionate number of families using institutional rather than family-based provision compared with white families. This is despite home-based services – such as sitting and befriending – being popular with BME families²⁴¹.

²³⁶ Hendey and Pascall (2002) *Disability and Transition to Adulthood: Achieving Independent Living*, JRF:York.

²³⁷ An estimated 60% of adults with a learning disability continue to live in the family home, with a further 20% heavily dependent of families for support in supported accommodation. (Russell, 2004). Not preparing disabled young people for independent living can lead to the situation of elderly carers.

²³⁸ The DTI's extended parental leave entitlement for parents of children entitled to DLA up to the age of 18 (The Maternity and Parental Leave (Amendment) Regulations 2001).

²³⁹ Emerson, E *et al* (2004) 'Levels of psychological distress experienced by family carers of children and adolescents with intellectual disabilities in an urban conurbation.' *Journal of Applied Research in Intellectual Disabilities* 17(1), June, 77-84.

²⁴⁰ Introduced under the Carers and Disabled Children Act (2000).

²⁴¹ Flynn, Ronny (2002), *Short breaks: Providing better access and more choice for Black disabled children and their parents*, The Policy Press/JRF.

*Families with disabled children are more likely than other families to approach the transition process from a position of poverty and disadvantage*²⁴²

The costs of raising a disabled child are estimated to be three times greater than those for raising a non-disabled child, and the costs increase as young people get older²⁴³. Many parents have to give up work as their child becomes an adult, due to the 'cliff edge' in support and services that they encounter²⁴⁴. Families are also affected by the loss of contribution to household income from disability benefits if young disabled people leave home or take up employment, this can be a barrier to parents supporting young people to become more independent²⁴⁵.

There is some evidence of what works in providing family support that bridges transition

The *Child Poverty Review* states that the Government will ensure "better family support services which are responsive to [families'] needs". The Review also highlights the importance of good quality options that enable parent-carers to

participate in paid employment²⁴⁶. These options must include families with older disabled young people. Local authorities should have regard to the Carers (Services and Representation) Act and Carers (Equal Opportunities) Act, recognising that the needs of family carers may also change at transition. Family carers should not have to give up paid employment or lose all family support services, just because their child is moving to adult provision.

Recommendations throughout this report will contribute to the provision of accessible mainstream leisure provision that empowers both parents and young people by providing age appropriateness, flexibility and choice. The Extended Schools Programme should also be key to the delivery of inclusive leisure options for older young people.

Financial constraints have been demonstrated to be a major barrier. The Family Fund has been evaluated as providing a cost-effective grant giving process that can make a significant impact to families

²⁴² Council for Disabled Children (2003) *Disabled Children, Their Families and Child Poverty: Briefing Paper End Child Poverty*: London. They are also more likely to be single parent households due to the increased rate of relationship breakdown between parents of disabled children (Shapiro, A (2004) *No time for us: relationships between parents who have a disabled child*, Contact a Family: London).

²⁴³ Strategy Unit consultation with parents of disabled young people. And Gordon, D. et al, (2000) *Disabled Children in Britain: A Reanalysis of the OPCS Disability Surveys*. TSO.

²⁴⁴ 84% of mothers with disabled children are out of work compared with 39% of mothers without disabled children. DWP (2002) *General Household Survey*, TSO.

²⁴⁵ Council for Disabled Children (2003) *Disabled Children, Their Families and Child Poverty: Briefing Paper End Child Poverty*: London.

²⁴⁶ HMT (2004) *Child Poverty Review* TSO.

with a severely disabled child²⁴⁷. However it only supports families with a disabled child up to the age of 16, and where the family income does not exceed £23,000 – irrespective of where they live in the country.

**Recommendation 6.4:
Family support that bridges
transition**

- Short term: DfES should review with the Family Fund, by 2006, how its remit could be extended to include families with 16-and 17-year-olds, and disabled young adults moving into independent living (including disabled care leavers), and whether the uniform income threshold should be raised.
- Medium to long term, the establishment of individualised budgets, as described in Recommendation 6.1, should reduce the need for supplementary grants and include continuing support for both young people and their families across transition.

6.4 Personalisation

Overarching vision for delivering personalisation and empowerment: by 2015, all young disabled people will have the opportunity to be fully involved in the personalised planning of their future activities and provision. This includes getting the right support (including advocacy) at school, from child and adult health and social services (where appropriate), from an informed personal adviser, and from all other relevant agencies and individuals.

Disabled young people and their families have poor access to advocacy and information

Disabled young people and parents of disabled young people told the Strategy Unit that little information²⁴⁸ about transition processes or options had been made available to them. Although there are good national sources of information they particularly wanted to find out what they were entitled to, who to contact, and what the options were *locally*. This can be particularly relevant to young people attending specialist residential provision in another area, and who are vulnerable to losing contact with services in their home authority. The fact that there is variable access to advocacy compounded this gap.

²⁴⁷ Beresford BA. (1993) 'Easing the strain: assessing the impact of a Family Fund grant on mothers caring for a severely disabled child.' *Child: Care, Health, Development*, 19: 369-378; Hirst, M (1997) 'Variations in take-up of the Family Fund' *Child: Care, Health and Development*, 23, issue 2, pp. 157-171(15); Family Fund (2003) *Annual review: A celebration of 30 years helping families*.

²⁴⁸ Such as the Transition Information Network magazine, seminars and website (www.myfuturechoices.org.uk) and the multi-media Trans-active programme for young people with learning disabilities, run by Mencap (www.trans-active.org.uk).

The focus on expanding disabled young people's participation in mainstream education, leisure, and social activities is welcome. But mainstream schools can lack the contacts and information that special schools have access to and a mainstream context can lead to some experiencing isolation from other disabled people.

What works in the provision of effective advocacy and information

The lack of information received by parents when their disabled child is first diagnosed is being addressed through the distribution of an Early Support Family Pack and Early Services Plan. Parents and young people consulted by the Strategy Unit keenly felt that such a pack – with its combination of accessible local and national information, and specified accountabilities – would also benefit those approaching transition to adulthood.

Box 6.8: Case study of provision of local transition information

Young disabled people in Suffolk have worked with child social services and Connexions to develop a transition resource to help other young people and their families. The DVD, called *No Limits*, includes detailed local information and will be distributed to all Year 8 pupils with additional needs in the

Authority. DVD stations are placed in Connexions offices, schools, other public places and are available on loan. The DVD will be updated annually and includes signing and other accessibility features²⁴⁹.

There are various local learning mentoring schemes around the country, and many provide more than support for learning, encouraging wider social inclusion and participation. However, a particularly good source of knowledge for disabled young people can be others with personal experience of encountering and overcoming disabling barriers. This can have added significance for young people from BME groups, who are more likely to experience isolation from others with similar experiences²⁵⁰.

Box 6.9: Case study of mentoring provided by disabled people

The mentoring project run at WECIL was a scheme aimed at empowering young disabled people by giving them one-to-one access to individual mentors who are disabled adults. The mentoring project has proved to be a small but significant model of innovative and progressive practice²⁵¹.

²⁴⁹ <http://www.nolimits.org.uk/>

²⁵⁰ Bignall, T., Butt, J and Pagarani, D. (2002), *Something to do: The development of peer support groups for young black and minority ethnic disabled people*, The Policy Press/JRF.

²⁵¹ Clarke, G (unpublished) *Mentoring Project final report: South Gloucestershire 1997-99*

Access to local user-led advice, information and advocacy services is discussed in Chapter 4.

These services will also ensure that young people and their supporters have full access to the advice, information and advocacy they need to move towards independent living. The proposed new duty on public bodies to promote disability equality will also require increased involvement of disabled people.

**Recommendation 6.5:
Young people and their families
should have access to good
quality local information**

DfES should, by 2008, work up and assess ways of providing local and national information about transition to disabled young people and their families, drawing closely on the experience of the Early Support Pilot Programme's Family Pack. The results of this work should be disseminated by 2008, through a range of avenues, for example, schools, Connexions, Independent Living Centres, and Parent Partnership Services. DH and DWP to contribute.

Disabled young people are not fully involved in the planning of their own provision and options

Planning for adulthood is not currently working well, and while there are examples of excellent local practice, there is also great

variation. Many young people, especially those with the most significant impairments, have little opportunity to develop a sense of aspiration or direction for the future, and analysis of survey data shows that disabled young people are much less likely than their non-disabled peers to feel that they have control over their lives²⁵². Many stay on at the school they previously attended because that was presented as the "easiest option"²⁵³.

Consultation with young people has found that where planning had taken place, many felt that they were not listened to or that their own preferences did not shape the options made available to them²⁵⁴. They also emphasised that maintaining friendships and a leisure life were issues of primary importance to them, but were not always regarded as important by others involved in planning. Under the Disability Discrimination Bill there will be a specific duty to involve disabled people.

What works in delivering person centred planning

Person-centred planning was developed through the Valuing People strategy to enable greater control over their support. Although Transition Champions and others have promoted its use with younger people, it was developed for use with adults with learning disabilities.

²⁵² Burchardt, T. (unpublished paper, work in progress).

²⁵³ Long, S. *et al* (2004) *What can I do when I leave school? A Review of Provision in Norfolk for Learners with Disabilities and Learning Difficulties*. Learning and Skills Council Norfolk.

²⁵⁴ Strategy Unit consultation with disabled young people in contact with services.

The evidence is still being gathered on what models work best for people with other complex needs and with children and young people²⁵⁵.

Box 6.10: Case study of the use of person-centred approaches in planning for transition

Trans-active is a project in which young people with and without severe learning disabilities work together, using multimedia to explore and communicate choices they will have when they leave school. The project has been launched nationally after development in 13 schools in Birmingham, Lichfield, and Lancaster. Over the year of participating in the programme, young people with learning disabilities develop a web-based 'passport', which they can use to show people what is important to them now and in the future²⁵⁶.

Those with the highest level of support need, especially where this includes communication impairments, need a considerable amount of time and specialist support in order to be able to engage fully in person-centred planning for their transition. This can be delivered well through multi-agency funding of specialist intensive transition workers,

which can also lead to increased efficiencies when run at a regional level²⁵⁷.

Box 6.11: Case study of sub-contracting the most specialist support

In Kingston, adult social care, children's services and Connexions all co-fund a team of transition workers to work closely with young people approaching transition and their families. This includes supporting the young people to develop person-centred plans based closely on their own areas of interest, and the families and young people to invite speakers and run seminars on transition issues they are interested in²⁵⁸.

Recommendation 6.6: Disabled young people should be included in planning that is centred on their own needs

- Short term: Within existing budgets, DfES should lead on disseminating good practice models for jointly-funded subcontracting of the most specialist transition support provision, from 2006 onwards. This should use existing or forthcoming vehicles, such as the Transition Information Network (TIN) or the practice development toolkit.

²⁵⁵ Valuing People are undertaking a large-scale evaluation of PCP, including five transition pilots, however other transition models are also being rolled out, such as Trans-active.

²⁵⁶ <http://www.trans-active.org.uk/index.htm>

²⁵⁷ E.g. the Greater Manchester Coalition on Autism Services.

²⁵⁸ Foundation for People with Learning Disabilities.

- DfES and DH should work up and assess a proposal to map youth centred approaches to transition planning, undertake pilots (involving, as appropriate, Children's Trusts, Connexions and/or Child and Adult social services) of different models to evaluate their suitability with different groups, and to inform the development of Individual Learning Plans that fit with existing assessment pathways. 2007 onwards.
- Long term: This should inform the promotion of person-centred planning practice nationally by 2010, informing how young people are involved in transition planning and the self-direction of their own support.

The Connexions service can provide effective support for disabled young people

The Connexions service national roll-out was completed in April 2003. Prior to this national roll-out, one in four young people with learning difficulties had been leaving compulsory education with no transition plan in place – despite the requirement for young people with statements of SEN to have such a plan under the Education (Special Educational Needs) (England) (Consolidation) Regulations 2001²⁵⁹.

Connexions has a number of key roles in relation to young disabled people, including:

- an overarching objective to reduce the number of young people who are not in education, employment or training (NEET);
- a requirement to coordinate the transition provision of young people with a statement of special needs from the age of 13 up to 25;
- to ensure young people with LDD receive assessments of educational and training needs in line with Section 140 of the Learning and Skills Act 2000; and
- to provide local LSCs with information to enable them to plan for and meet the educational and training needs of young people with 'Learning Difficulties and Disability' (LDD).

Evidence shows that despite being new, Connexions has engaged positively with disabled young people, with high levels of satisfaction (92%)²⁶⁰ with the service they receive – the same as that of non-disabled young people. Whilst other evidence shows that young people, their carers and partner agencies identified three key qualities in their Connexions Personal Advisors: expertise and information giving; support in speaking up/advocacy; and independence.

²⁵⁹Heslop (2002).

²⁶⁰BMRB Social Research (2004) "Improve your Connexions: the Connexions Service customer satisfaction survey".

The National Audit Office (NAO) has also reported that the Connexions service is on course to achieve its target for the reduction in the number of young people who are NEET. And because of the often multiple barriers disabled young people face, the Connexions service has to support them if it is to successfully deliver its NEET target.

Nevertheless, more could be done. The NAO has noted that “There is still a risk that not all young people who would benefit from advice are receiving it. This gap is due to Connexions operating with fewer resources than was originally anticipated, together with a lack of clarity regarding the respective role of schools and the Connexions service in providing careers advice to young people. Closing this gap would help ensure that young people make the most of their opportunities²⁶¹.” These issues are likely to be particularly important in determining the success of Connexions as a service to disabled young people. Working with disabled young people typically requires more time and additional expertise, compared with what is required for other young people. Some disabled young people, who are less “work ready”, may require significant levels of support to enter employment or continue learning.

Also, in focusing efforts on the 16 to 18 year old NEET, it will be important to ensure that the target

delivers action which benefits the full range of disabled young people who may otherwise be NEET. In particular, it is important to consider that some disabled young people do not leave special school or college until they are 19 or 20, meaning that they are at risk of becoming NEET at a slightly older age than the 16–18 year old group on which attention may otherwise be focused.

Research has shown that where Connexions Personal Advisers have the time and the training to develop properly a relationship with, independently advocate for, and continue to support disabled young people beyond age 19, young people value this highly and the experience of transition is improved. But often this relatively new ‘transition co-ordination agency’ has lacked the financial and skills-based resources to perform this role²⁶².

Box 6.12: Case studies of Connexions’ work with disabled young people

Connexions South Central sub-contracts a specialist transition worker from Hampshire Deaf Association to work with students in particular schools and to provide advice to other Personal Advisors.

In Somerset, four Connexions workers are based in adult learning disability teams and this has led to much better

²⁶¹ National Audit Office (2004) Connexions Service: Advice and Guidance for all young people report by the comptroller and Auditor General HC 484 Session 2003-2004.

²⁶² Rowland-Crosby, N. (2004).

information sharing and strategic planning, leading to improved commissioning of services to meet the needs of young people with high support needs²⁶³.

**Recommendation 6.7:
Ensuring advice and guidance
is tailored to meet the needs of
disabled young people**

From 2005, DfES should ensure, as part of the Youth Offer to be developed as a result of the forthcoming Youth Green Paper, that arrangements for providing advice and guidance to young people, including Connexions, meet the needs of all disabled young people.

6.5 Opportunities through on-going inclusion

Overarching vision for opportunities through on-going inclusion: by 2015, all disabled young adults will have the expectation and availability of a breadth of valid and valued opportunities available to them, irrespective of the complexity of their needs. This includes supporting inclusion within mainstream education, employment and training, and enabling personal development, active citizenship, and community involvement opportunities for all.

The situation for disabled students in higher education (HE) was

described in the Interim Analytical Report from this project, and is not repeated here. While the numbers are still low, there has been a sustained increase in the proportion of disabled people participating, alongside a large increase in the number of students receiving Disabled Students Allowance (DSAs). The introduction of early needs assessment for the DSA has helped to smooth this transition. Participation in HE has been found to play a key role in reducing the gap in occupation outcomes between disabled and non-disabled people²⁶⁴.

Disabled young people's needs are often not met by current further education provision

Alongside the welcome modernisation of daycentres there has been a radical shift in the role of the further education sector. More young people with learning disabilities are attending college, but there has not been a strategy in place to ensure that the nature and capacity of this provision is meeting students' needs. Further education (FE) colleges have been described as at risk of becoming 'the new daycentres' due to segregated provision, a narrow curriculum focused on basic numeracy and literacy, a lack of clarity on a range of pre-level 1 core skills, and students continuing to undertake a 'revolving door' of repeated courses without a sense of progression,

²⁶³ Robinson, C (unpublished) Good practice examples in transitions from the South West.

²⁶⁴ Groucher K (2004) 'What Happens Next? A report on the first destinations of 2002 graduates with disabilities' The Skill Journal, Issue 79.

despite their goals and abilities²⁶⁵. Another barrier to greater inclusion is the emphasis in government targets on achievement of a level 2 qualification as the minimum required to participate in a modern economy and fixed ways of measuring educational success²⁶⁶. There is also an assumption that achievement at FE occurs by age 19, while two-thirds of disabled FE students are age 20 or over²⁶⁷. The production of a Disability Equality Scheme, if required under the Public Sector Duty, would be one way to challenge FE institutions to address the equality of provision offered to disabled students.

The increased role for the FE sector has led to various agencies developing new workforce qualifications in SEN provision. This duplication and fragmentation could be avoided if a single and wider strategy was developed.

There is some evidence of what works in delivering inclusive further education

The Learning and Skills Council (LSC), with newly defined

responsibility for disabled learners aged 16 or over in school and further education, is undertaking a national review of the planning and funding of provision for 'learners with learning difficulties and disabilities' across the post-16 sector²⁶⁸. Every local LSC is leading on a Strategic Area Review (StAR) of provision in their region, supported by LEAs and other key stakeholders, including employers. Some local LSCs have addressed the needs of disabled learners²⁶⁹. It is important however that the national LSC can take a strategic lead on the provision needed for this group of learners (including in terms of workforce skills) and how it might be planned and funded within the LSC's statutory duties.

Box 6.13: Young people with learning disabilities identified a range of outcomes they wanted to achieve through studying, including to:

- gain qualifications and be employable;
- gain independence, advocacy and self-assertiveness;

²⁶⁵ Long *et al.* (2004) and Lockton, P (2003) *Mapping the provision of learning for learners with learning disabilities in Nottingham and Nottinghamshire*, LSC: Nottingham.

²⁶⁶ A survey conducted in 1995 estimated that nearly half of disabled students in FE (mostly those with LDD) are following a pre-level 1 course. IES (1997) *Mapping Provision: The Provision of and Participation in Further Education by students with Learning Difficulties and/or Disabilities*. FEFC: Coventry

²⁶⁷ Half of disabled students in FE are aged 25 or more, so the focus on the 16-18 band does not meet the needs of the majority of disabled FE students. (IES (1997)). A higher proportion of disabled FE students record their ethnic origin as 'white' than for the student population as a whole. IES (1997).

²⁶⁸ The Scottish Further Education Funding Council has recently undertaken a similar review of funding and administration of SEN provision in Scotland.

²⁶⁹ E.g. Long *et al.* (Norfolk) and Atkinson E (forthcoming) *Improving Choices Eastern Region*.

- develop an understanding of computers and IT;
- develop practical work skills;
- learn basic and daily living skills; and
- learn about themselves and relationships²⁷⁰.

The above suggests a need for individually-tailored programmes that balance 'basic' numeracy and literacy skills with a greater emphasis on skills of decision-making, advocacy and empowerment. This needs to cover both vocational learning and learning as an end in itself (music, art, drama) and combine both classroom and practical or work-based experience (discussed in the next section).

The final report of the Tomlinson Group on 14 to 19 year Educational Reform contains proposals designed to meet the needs of all learners, including a 'customised' pre-foundation level diploma designed to be personalised to the individual and to measure distance travelled. If adopted, this could meet some of the present concerns about addressing SEN and disability issues in the FE sector. However it will need to avoid becoming an additional transition plan for disabled young people.

Box 6.14: Case study of accessible and inclusive FE provision

The new E2E course in Nottinghamshire is aimed at young people with a variety of needs and abilities and links with progression into employment, work-based training or further education. Through consultation and person-centred planning a long-term action plan is agreed and shapes the individual's curriculum, in addition to a core curriculum that includes: citizenship, action planning, rights and responsibilities, and accessing/using information.

Disabled young people often struggle with the transition from education to work

As discussed in Chapter 7 and the Employers Working Group report, for a large proportion of disabled people, access to skills and employment is poor. At the age of 26, disabled people without learning difficulties are more likely than non-disabled people to have no qualifications, to feel that they have not acquired useful skills, not in education, employment or training, and if they are in employment, to be in unskilled work²⁷¹.

Progress from vocational courses to employment is problematic, especially for young people with learning disabilities. A recent review

²⁷⁰ Long (2004).

²⁷¹ Burchardt (unpublished paper, work in progress) – figures exclude those with an intellectual impairment.

could find few examples of transition to work provision, and funding sources for these were fragmented and fragile. Education and training courses are often too general and insufficiently focused on the main transition to employment aims of the individual²⁷². Programmes aimed at helping young people enter the labour market – such as new Apprenticeships²⁷³ and the New Deal for Young People²⁷⁴ – make little provision for disabled young people's additional needs. Other employment initiatives, like Pathways to Work, Access to Work, and the New Deal for Disabled People, focus more on return to work and retention than on entering the labour market for the first time.

The introduction of new legislation, around child protection and health and safety, may further hinder disabled young people's access to work experience and volunteering by promoting a risk-averse culture amongst employers. In addition, work experience and volunteering are not fully covered by the DDA or by Access to Work.

Box 6.15: Case study of the barriers to accessing work experience

Philip found himself a work experience placement in a media company in a nearby city doing

work he is extremely interested in. However because his mainstream school lacked the funds to conduct a full risk assessment of the premises, to insure him, or to contribute towards his transport costs, he was unable to attend²⁷⁵.

There is some evidence of what works in making the transition to employment

Key factors identified for a successful transition to work provision, particularly for young people with learning disabilities, include:

- recognising that employment is a realistic option;
- developing training packages to support the individual;
- identifying employment goals early on; and
- providing flexible and supported work experience placements, with on-going support for the individual and employer.

These can be developed through improved links between college and employers. Employers are often very supportive, and in consultations with the Strategy Unit have highlighted the need for more information and good practice examples.

²⁷² Jacobsen, Y (2002) *Making the Jump: Transition to work, a guide to supporting adults with learning difficulties make the jump from education to employment*. NIACE: Leicester.

²⁷³ The SU welcomes the extension of Apprenticeships to those aged 14 to 15 and over 25.

²⁷⁴ The New Deal for Young People, launched in 1998, seeks to improve the long-term employability of 18 to 24 year olds who have been unemployed for six months or more.

²⁷⁵ Strategy Unit consultation with disabled young people.

Box 6.16: Case study of joint working between further education and supported employment services

Mencap Pathway Employment Service was setup in 1998 to assist people with learning disabilities into employment. Its office is situated in the Harrow College building, and Harrow College part funds the service. Individuals are supported through training for work, liaison with employers, organising and supporting work experience placements, providing job club facilities, support at interview and on-the-job, and benefits advice.

The Tomlinson Group's proposals for 14- 19 educational reform include integrating vocational pathways, Apprenticeships, and work-based training into the common Diploma. If adopted, this new system has the potential to work well for disabled young people, but it will be crucial that any new arrangements are thoroughly disability-proofed to make sure that they do.

Recommendation 6.8:

Disabled young people to have full access to individualised learning and vocational pathways into chosen employment and other meaningful occupation opportunities

- Short term: DfES and LSC, from 2006 onwards, should ensure in response to the Tomlinson group's recommendations for 14 to19 educational reform that any new arrangements address the needs of disabled young people²⁷⁷.
- Good practice examples should be issued to employers and ACAS on implications of new Health and Safety legislation and child protection regulation, in particular with respect to provision of work based training and experience. DfES to lead from 2006 onwards.
- DfES and LSC should make sure that the Lifelong Learning UK sector skills council being established to represent employers in the post-16 sector has a remit to develop appropriate career structures and skills development opportunities for all staff working with young people with SEN. 2006 onwards.

Many disabled young people continue to move into segregated adult lives

Disabled young people with the most severe impairments continue to be offered inappropriate segregated adult services (or in some cases be offered no support at all because they are seen as 'too

²⁷⁶ Jacobsen (2002).

²⁷⁷ Including the role of Shaw Trust, Papworth Trust, Trident, regionally commissioned Education Business Alliances/Links, youth-focused social firms, links between FE and employers through work coaches and supported employment, flexibly designed work experience options, and the role of E2E.

disabled' for local provision). At a systemic level, incentives need to be created for moving resources from day services and repeat 'special' college courses into mainstream leisure, cultural, sport and social opportunities, under the disabled person's control. This can be hindered by the lack of research exploring meaningful life options for those with the most significant impairments, for whom full-time employment may not be a realistic option.

Disabled young people may need longer to progress through courses and get to different aspects of transition. However most transition services tend to be available at school leaving age, which often does not coincide with the right time for other aspects of transition²⁷⁸. Mental health needs are often associated with having other impairments – but disabled young people's access to such services is often very poor^{279, 280}.

The same issues that non-disabled young people have to deal with – learning about sex, relationships, bullying, and drug and alcohol usage – are also relevant to disabled

young people, with all types of impairment. The move to involve young people in wider consultations on a range of public issues has not always addressed including young people with impairments²⁸¹.

Box 6.17: Case study of development of inclusive leisure provision

Kidsactive run a Play and Youth Development Project, funded by Wandsworth Council, to promote inclusive play and leisure opportunities for disabled children and young people up to the age of 21. It works with disabled young people to find out what they want and encourages leisure providers to make their services accessible to all young people. The project provides information on inclusion and disability issues to parents, carers, young people and professionals; assists with moving disabled young people into non-specialised provision; and runs disability awareness training to enable mainstream leisure facilities to ensure their services are accessible to all²⁸².

²⁷⁸ Pownceby et al (1997) *The Coming of Age Project: A study of the transition from paediatric to adult care and treatment adherence amongst young people with cystic fibrosis*. Bromley, Kent: Cystic Fibrosis Trust.

²⁷⁹ Projects are underway extending CAMHS services at transition (NSF for mental health).

²⁸⁰ Maudslay, L (2003) 'Aasha Project: transition to adulthood for young people with learning difficulties from a south Asian background' *Skill Journal Issue 77*.

²⁸¹ The Consultation Fund makes grants available to voluntary and community sector organisations to run consultation activities for children and young people in England up to and including age 19. Disabled young people have been identified as a key group. Changemakers, a national charity which promotes young person led action and learning, is managing the annual fund of £500,000 on behalf of the DfES.

²⁸² <http://www.kidsactive.org.uk/>

**Recommendation 6.9:
Access to leisure and independent
living needs to be ensured**

- Short term: The Code of Practice produced by DRC outlining the duty on the public sector to promote disability equality should include local authorities proactively working with a range of stakeholders, including the leisure industry, to increase opportunities for participation for disabled people within their area. DWP to lead, from 2005 onwards.
- From 2005 onwards, DH to commission research on the range of meaningful adult life options for young people with the highest levels of need (within existing research budget), and use this to inform the menu of options explored through Community Access Assessments.

Chapter 7: Employment

Summary

Recent Government policy has delivered some significant improvements in the employment prospects of disabled people – but further action is needed to support disabled people in the labour market.

Recommendations to support independent living will play a key role in supporting disabled people to get and keep jobs. But there is a strong case for more focused action, so that any disabled person who wants a job, and needs support to get a job, should be able to do so wherever feasible. Employers should also be supported in employing disabled people.

To achieve these goals, this report highlights five areas of intervention:

- providing effective early support and guidance to those who need it to overcome barriers to work;
- improving the skills and access to in-work support needed to enhance disabled people's employability;
- connecting disabled people with work by making transition to employment less risky and complicated;
- engaging employers to improve their attitudes towards disabled people and their understanding of what it means to employ a disabled person; and
- building information networks to bring together and disseminate important information to disabled people, their employers, family, friends and carers.

Services should be personalised with a strong focus on delivering support tailored around individual needs. Specialist case managers would need to take responsibility for guiding and assisting disabled people through all stages of support and all the way to open employment where this is appropriate.

The chapter sets out the current situation for disabled people and the labour market in Section 7.1. The next section (7.2) discusses the importance of effective early support, including rehabilitation. Section 7.3 sets out recommendations to improve the employability of disabled people. Section 7.4 addresses connecting disabled people with work and work support. The role of employers is discussed in Section 7.5. The last section (7.6) highlights the importance of building information networks.

The focus of this chapter is on disabled people who are out of work. As Chapter 2 has noted, this is not necessarily the same group of people as those claiming incapacity-related benefits. However, there is a significant overlap, and many disabled people can be most effectively supported through interventions targeted through elements of the benefits system²⁸³.

7.1 What is the current situation

Disabled people are doing less well than non-disabled people in the labour market

Before 1997, there was little incentive or assistance for people to move off benefits and into work; nor was there much incentive or assistance for employers to employ disabled people.

A number of changes have been made since 1997, including the strengthening of the Disability Discrimination Act, the New Deal for Disabled People, and the National Minimum Wage. Improved childcare provision and flexible working hours have also helped disabled parents to move into and stay in work. These changes have improved incentives and assistance for people to move off benefits and into work, and have placed additional requirements on employers to employ disabled people. However, more work is still needed to improve the labour market status of disabled people. The scale of the challenge to improve the employment chances of disabled people is still significant.

Most recently, DWP has introduced the Pathways to Work pilots, which are re-focusing the framework of support for people on incapacity benefits to help more people get back to work. This approach is testing out many of the key principles identified in this chapter, and early results suggest they are proving very effective.

Box 7.1: The Pathways to Work pilots

Pathways to Work pilots are the Government's most concerted effort to encourage and assist those people on Incapacity Benefit (IB) to return to work, and work with key stakeholders to promote the value of job retention.

²⁸³ Previous chapters have also addressed issues around the support that parents of disabled children need. Some of the recommendations of Chapters 4 and 5 will help parents of disabled people into work by offering the right support, such as childcare.

Existing claimants can also take part on a voluntary basis. The aim is to enable people to overcome obstacles to work, by focusing on their capabilities and thereby challenging the belief that people with health conditions are incapable of work.

The Pathways to Work pilots are running successfully in seven areas of England, Scotland and Wales, covering 9% of new claims to IB. The key features are:

- more skilled advice and help to return to work provided by specialist IB Personal Advisors;
- direct access for customers to existing programmes and the newly introduced condition management programmes offered jointly by Jobcentre Plus and the local NHS;
- improved financial incentives to move into employment, such as the Return to Work Credit;
- more support for those moving from IB to Job Seekers Allowance – including mandatory early access to mainstream New Deals; and
- active engagement of stakeholders, including GPs and employers, in the merits of getting people back to work.

Budget 2004 announced that people who have been claiming IB in the two years before the pilots

will be brought into the WFI regime from 2005 in Pathways to Work areas. These interventions will be included in the evaluations. These include a Job Preparation Premium of £20 for those undertaking relevant activity that supports return to work.

In addition, the Pre-Budget Report (PBR) announced that Pathways to Work pilots will be extended, starting from October 2005, to cover around one third of the country.

The intention is to evaluate these pilots. Early evidence from the first phase pilots shows some very encouraging early results in terms of increased off-flows from benefits, higher levels of job entries and significantly increased participation levels in back to work activity.

The report endorses the current DWP initiatives within the Pathways to Work pilots. It welcomes the PBR announcement and supports it. It proposes for DWP to roll out Pathways to Work nationwide, subject to evaluation results from the current pilots and subject to the availability of appropriate resources.

Some of the recommendations in this report are focused on issues not within the scope of the Pathways to Work pilots. These recommendations should be taken forward alongside progress with

Pathways. Other recommendations propose variations or additions to elements already within the pilots. These recommendations should be taken forward as part of the roll-out of Pathways.

7.2 Effective early support

Long-term and permanent incapacity is not inevitable.

This section focuses on those people who become disabled as adults. Early intervention can provide support and information to the individual to manage their condition and remain employed.

Rehabilitation is an important component of the overall package of support. And an effective gateway onto incapacity benefits – based on a rigorous fair, prompt and efficient assessment process – can be used as a tool to identify the right support needed.

Rehabilitation is an important component of the overall package of support that enables disabled people to overcome barriers to work

There is widespread acknowledgment that considerably more people could be retained in and helped back into work. There are several reasons why so many people do not receive the right help at the right time.

- Despite the high costs to employers of sickness absence – an estimated £11 billion per year – many employers do not take steps actively to monitor or deal with sickness absence. The largest

employers are increasingly recognising the high costs, and that they can do something about these through better management and attention. But many employers continue to regard the individual's health and relationship with the GP as private and nothing to do with them.

- GPs have little time to pay attention to work and contextual issues, and may feel obliged to sign-off patients without helping with return to work plans. Some may even still see work as part of the problem rather than the solution. Few GPs receive adequate occupational health training.
- There remain pervasive and negative cultural expectations towards working when less than fully healthy, with IB seen as something you can simply “pass on to”.
- Occupational health (OH) services are not easily available to provide the vocational rehabilitation required, whether to employers, to GPs wanting to refer patients, or to individuals. The UK has a much lower provision of OH than other European countries and supply may not be sufficient, despite schemes such as NHS Plus²⁸⁴. Services vary in local availability, lack volume capacity, and can be targeted and marketed to a restricted group.

²⁸⁴ NHS Plus is a network of OH departments across England supplying OH services to business at a cost, with a focus on SMEs

- There is no recognisable map or structure of provision and therefore a poor basis for capacity building and market development, or for ready access by customers.
- It remains uncertain which specific interventions work best. Whilst there is evidence that Vocational Rehabilitation (VR) works there is little precision beyond a few conditions such as back pain and asthma as to which formats and contents work best with particular client groups and conditions. However, this general lack of evidence seems to hold back progress even where the evidence is strong.
- Vocational rehabilitation can be seen by health professionals as separate from rehabilitation from injury or illness, with some danger that the more that VR is successfully promoted, the more comfortable it can be for some health interests to sustain a narrower perspective than 'rehabilitation for whole life'.
- The changing nature of conditions, with the presentation of many non-specific often psychological symptoms, has led to uncertainty of treatment.
- Interventions often happen too late, and only when options for treatment of medical factors has been completed, when the individual's motivation and work

connections have declined too far, and when non-employment has become a stable feature of their life.

Box 7.2: Current initiatives with a link to rehabilitation

- DWP has published a "Framework for Vocational Rehabilitation", which pulls together information about best practice, research and available capacity, and will be developing a strategy for VR through a broadly representative steering group alongside groups on research and standards.
- DH has published the White Paper "Choosing Health" and is planning a Green Paper on Adult Social Care which together with the DH five year plan, the NHS Improvement Plan, the NSF on Long Term Conditions, and initiatives on Chronic Disease Management, will provide significant opportunities to advance work as a component of good health.
- Government has accepted the recommendations of the Better Regulation Task Force report "Better Routes to Redress" for DWP to develop mechanisms for earlier VR interventions, and for DH to work with partners in government to improve the provision of NHS rehabilitation services.

- The Job Retention and Rehabilitation pilot is being jointly run by DWP and DH, and is aimed at showing whether retention in work of people falling sick is best secured by employment focussed support, health biased support, or a combination of the two.
- The Pathways to Work pilots are testing of a range of policy changes including the provision by the NHS under contract to Jobcentre Plus of "Condition Management Programmes".
- The Scottish Executive has established "Healthy Working Lives" to improve occupational health provision.

If rehabilitation is going to form an effective part of an overall system for supporting disabled people into sustained employment, then current approaches will have to change. Instead, the system should aim to enable individuals to:

- identify their specific circumstances (especially sickness versus impairment) and provide rehabilitation accordingly;
- remain in work for longer when sick;
- return to work easily and smoothly from Incapacity Benefit;
- recover from injury and illness;

- move from "cannot work" to "considering work";
- move into supported employment; and
- be able to carry out activity that is personally considered useful.

Analysis carried out for this report suggests that such a system would require:

- many more people to be assisted to think about and progress towards work as an explicit outcome of rehabilitation;
- individuals with health problems to be empowered to access at an early stage, typically three to four weeks from onset of changed condition, whatever help they need to look for and retain work or return to work;
- employers to act swiftly and assertively, along with GPs, to engage with employees falling sick, to support their early return to work;
- recognition that rehabilitation requires the active contribution of primary care and secondary care as well as vocational private and public providers with effective partnerships between them; and
- training and support to be provided to employers and GPs.

There are a number of ways that this might be achieved – through a

combination of incentives, statutory requirements, investments and guidance applied to individuals, health professionals, organisations and employers. There may also be significant roles for the insurance and voluntary sectors.

**Recommendation 7.1:
Rehabilitation**

DWP/DH should develop and launch by 2008 a set of arrangements for provision of vocational rehabilitation which assigns responsibilities and apportions responsibility for costs, is available and accessible to those in work at risk of losing their jobs, to those on Incapacity Benefit seeking to return to work, to those on Job Seekers Allowance; and to employers and agencies working in support of these people.

Achieving this recommendation should involve:

- building a firm evidence base through development of the DWP Framework for Vocational Rehabilitation, lessons from the Job Retention and Rehabilitation pilot, evaluation of the Condition Management Programmes running within the Pathways to Work pilots, and testing the HSE model for supply of occupational health and safety and return to work support to different client groups and employment sectors;

- building up capacity in occupational health, through dedicated services in the private sector, and in the public sector such as NHS Plus;
- securing greater focus upon work and employment throughout the NHS and private sector health services, in line with the White Paper "Choosing Health";
- structuring rehabilitation services more clearly for the benefit of all those who need them, supply them and guide people to them;
- reappraisal of the roles, competences, deployment, training and workforce planning of health professionals for effective rehabilitation; and
- considering how far employers and others can be expected to bear the costs, and the extent to which there is a case for the taxpayer to bear costs, consulting with business.

Progressing these actions will require leadership and assigned responsibilities through:

- new arrangements for joint working between DH and DWP taking advice from DTI, HSE and Jobcentre Plus, with ministerial direction through the Health Safety and Productivity Task Force or similar group; and

by DH inviting the Academy of Royal Medical Colleges to examine what more can be done to stimulate greater attention to work as a positive driver for good health, and the implications for the professions involved.

Recommendation 7.2a: Occupational health

DH and DWP should, from 2008 onwards, encourage increases in the supply of quality OH provision:

- Encourage more trainees and raise professional standards.
- Consider a wider range of delivery channels, for example, by allowing different related professionals to take on some of the duties currently requiring a qualified OH therapist, and making more use of low cost delivery channels such as telephone consultations, and encouraging OH champions in PCTs.

Recommendation 7.2b

DH and DWP should, from 2008 onwards, encourage a greater number of employers to provide OH service to their employees.

- DWP and DH to research the business benefits, including value for money, of expenditure on OH. This should include research into levels of awareness of OH services among SMEs, and reasons why they are not used.

These benefits, together with practical examples of what works in rehabilitating and retaining workers, should then be disseminated to business.

- DWP and HMT to engage with the Association of British Insurers and employer representatives to consider how income protection insurance premiums can offer better incentives to employers to monitor and deal with sickness absence.

The current gateway to incapacity benefits is weak and poorly policed

Currently GPs are the main guardians of the gateway to incapacity-related benefits.

They have the overall responsibility for managing clients' condition and are also required to provide medical evidence to support patients' claims to Statutory Sick Pay (SSP); or Income Support or Incapacity Benefit for those currently without employment. GPs are required to issue regular statements, judging whether their patients are fit for work until the Personal Capability Assessment test has been applied.

The medicalised approach is typically not appropriate

In general, GPs have dealt with disabled people within the remits of the medical model of disability, and responding to their patients' needs by focusing on their functional impairment or ill health rather than recognising how external factors,

such as access to the right equipment or support at work will affect them.

GPs lack information

GPs can have great influence on the individual's decision whether to return to work. To be able to offer such advice GPs need to have a greater awareness than at present about the health-related benefits of working. However, many GPs experience a number of difficulties in judging capacity for employment, including assessing subjective or difficult to measure conditions such as back pain, maintaining a good GP-patient relationship and having little or no access to specialist occupational advice²⁸⁵.

GPs are not effectively linked to employers or to Jobcentre Plus

Most GPs have had no direct contact with Jobcentres and are unaware of existing employment programmes or are misinformed of available routes into employment to those on incapacity-related benefits. There are situations where benefit dependency is ingrained in the community or family culture, and GPs may feel that adjustment to a new pattern of life would be very difficult for those people²⁸⁶.

GPs face a heavy workload

There is wide recognition of the added pressure on GPs' time created by paperwork, which includes medical certificates and other forms.

GPs provide a number of services including health care, medical advice on their clients' conditions and valuable information to assist DWP doctors in their assessment process. Lack of available time is often used to justify GPs providing poor quality evidence to DWP.

DWP is aware of the need to increase GPs' awareness and understanding of the health benefits of working. DWP issues guidance to all doctors stating that they should always carefully consider whether advising a patient to not go to work is the most appropriate response to their condition. There are also a number of initiatives (Box 7.3) to improve training and awareness of GPs in this area.

Box 7.3: Examples of current GP Initiatives

DWP are currently introducing a series of initiatives targeted at strengthening the information and training given to GPs on fitness for work advice and certification practices. These include:

- a series of GP information aids, supported by the Royal College of GPs, Faculty of Occupational Medicine and the Department of Health, with advice and guidance on fitness for work, completion of sick notes, communicating with employers and evidence-based recovery periods following a range of surgical procedures;

²⁸⁵ Hiscock, J and Ritchie, J (2001) "The role of GPs in sickness certification", Department for Work and Pensions, Research Report No 148

²⁸⁶ Hiscock and Ritchie (2001).

- videos and DVDs with information about health conditions, advice from medical experts, IB assessment procedures and the benefits of work;
- Internet based resources with further guidance on health and work, the certification process, and official guidance on certification;
- an interactive online learning site with an 'approved' module on certification practice and, from February 2005 in conjunction with the HSE, a module about Occupational Health;
- phase 1 development, with Cardiff University, of GP learning products on motivational interviewing for difficult consultations;
- sponsoring of systematic reviews to describe good practice in a range of areas including sickness absence and returning people to work;
- national conferences for GPs and other medical practitioners on certification and return to work initiatives; and
- presentations at postgraduate meetings and seminars from DWP doctors and doctors from medical services.

Recommendation 7.3:

The role of GPs

DWP and DH should, by 2007, work together in identifying, and in assisting GPs to adopt, best practice in patient care, taking account of the most recent evidence of the beneficial health effects of work, in the context of GPs' role in providing advice on fitness for work.

This might include:

- defining good clinical practice in this area, collected by a credible, independent body acceptable to doctors involved in primary care, and formulated into evidence-based guidelines for GPs;
- developing a concerted implementation plan and an educational/behaviour-changing campaign to get the messages across, especially in undergraduate training;
- introducing effective recording and monitoring of GP certification, so that quantitative data can be collected and the certification practices of GPs can be measured (much as their prescribing habits), and that information used to:
 - monitor individual GP certification performance; and
 - link performance to retraining and re-validation; and

- providing a system which allows feedback to GPs about their certification practice that highlights good and bad performance against evidence-based guidelines.

The process of assessing disability status is fragmented and long

There are five main ways of assessing disability within the current benefits and tax credits system.

- *Incapacity for work* consists of two main tests of incapacity used for SSP, IB and IS:
 - Own Occupation Test assesses an individual's ability to do his or her usual job; and
 - Personal Capability Assessment (PCA) assesses an individual's ability to carry out a range of activities.
- *Needing care, supervision or watching over by another person* is used for the DLA care component and Attendance Allowance (AA).
- *Unable or virtually unable to walk* is used for Disability Living Allowance's mobility component and for war pensioner's mobility supplement.
- *Degree of disablement* is used for Industrial Disablement Benefit, War Disablement Pension and Vaccine Damage Payments.

At a disadvantage of getting a job is used for Working Tax Credit (WTC); to qualify for the disability element of the WTC one must pass a separate "disability test"²⁸⁷.

Eligibility to claim for one benefit may also result in that benefit being the gateway to further claims. Numerous interactions exist between DLA and other benefits. Most importantly, entitlement to DLA highest rate care component exempts people from the PCA assessment and can therefore lead to IB entitlement (if people have sufficient National Insurance Contributions), with the exception of children who may get DLA but will not get IB. In cases of dispute where IB disallowance has taken place, DLA entitlement can influence decisions on IB entitlement at the stage of appeal.

The length of time it takes to get a decision through the PCA is also important. Clearing new cases by DWP medical services currently takes on average 13 weeks, while re-referrals take up to 20 weeks. The length of the PCA – sometimes taking months to reach a decision – can hamper return to work activity.

There are practical limits to how early in the benefit claim the PCA can take place.

- There are capacity issues linked to numbers of doctors.
- There are risks of unnecessary PCAs and quick repeat PCAs being

²⁸⁷ In addition, registering as disabled with local authority social services departments requires that a person is assessed as being "substantially and permanently disabled". The same applies for getting a disability reduction in council tax.

required because a condition might be unpredictable in the early stages – and so further increasing static resource, labelling people as incapacitated early on rather than letting them leave of their own accord or GP action which may discourage early departure from IB.

**Recommendation 7.4:
Benefits assessments**

By 2008, DWP should review the overall process of assessing eligibility for disability-related benefits and investigate whether different assessments are appropriate in all cases or whether there is any scope for bringing them closer.

Following the results of the Pathways pilots, by 2006 DWP should identify whether the PCA is at the nearest optimum point to the start of the claim, or can be further repositioned.

The Personal Capability Assessment measures only functional capability

The PCA currently assesses abilities and disabilities of a person against an “abstract concept of work”. The PCA assesses claimants in their ability to perform certain functions, e.g. walking, standing, seeing, hearing. The assessment is used to divide those required to search for work (on Job Seeker’s Allowance (JSA)) from those with no work requirements. Once the claimant

is eligible for IB, they are no longer required to search for work.

The main focus therefore remains incapacity. The PCA does not provide an assessment of the residual capability, and certainly does not identify what steps would be needed – rehabilitation, training, workplace adjustments, etc – to enable the individual to return to work. However, DWP is currently piloting Capability Reports in the Pathways areas to provide work-focused information about clients’ conditions or impairments. They are carried out in pilot areas in 70% of the cases in which a DWP doctor carries out a face-to-face interview as part of the PCA process.

Lessons from the original trial of these reports have been applied to the use of Capability Reports in Pathways to Work pilot areas. Evaluation prior to the Pathways to Work pilots showed that Capability Reports have little impact on a person returning to work but this is mostly due to poor Personal Advisor training and lack of skills and awareness, which the Pathways to Work pilots may be able to address²⁸⁸. Emerging anecdotal evidence from Pathways pilots is much more positive. Further benefits could be expected from an approach which moved beyond functional impairment to address the range of barriers faced by a disabled person in looking to return to work.

²⁸⁸ Legard, R., Lewis, J., Hiscock, J and Scott, J. (2002) Evaluation of the Capability Report: Identifying the Work-Related Capabilities of Incapacity Benefits Claimants. Research Report 162, Department for Work and Pensions.

Recommendation 7.5: the Capability Report

2005 onwards, DWP should roll out the Capability Report nationwide, subject to evidence, as part of the national expansion of Pathways to Work. A strong focus must be placed on widening over time the scope of – and input to – the Capability Report and assessing the level of support, including training requirements or condition management programmes, on individual needs in order to progress into the workplace.

- This can be a joint process with input from DWP medical services, Personal Advisers and employers, giving a complete picture of an individual's capabilities and support needs.
- The process must be coordinated by the Personal Advisor with a special focus on general labour market issues (skills and work, local labour market knowledge etc) and job retention.

7.3 Improving employability

Disabled people often have few or no educational qualifications, which places an important obstacle on their path into employment. Low educational attainment translates into low skills and hence low employability. In addition disabled people require support in the form of equipment, transport, structural changes to their working environment or support workers.

Currently, responsibility for training and support is shared between employers, employees and state provision. A more integrated response would improve disabled people's employment chances and empower them to fulfil their roles and responsibilities.

Disabled people are not benefiting enough from government-provided training

The adult skills system is the responsibility of the Learning and Skills Council (LSC) which provides education and training for six million learners over the age of 16. Its priorities include reducing the number of people without basic skills and making training available to all sections of society.

Disabled people do not benefit as much as the general population from government-provided training – only 9.5% of learners in LSC-funded provision are disabled, although 20% of the working age population are disabled.

The Learning and Skills Council has duties under the Learning and Skills Act 2000 to promote disability equality in all its programmes and to have regard to the needs of disabled learners. In line with its statutory duties, the LSC is currently reviewing its planning and funding of provision for learners with learning difficulties and/or other impairments.

Recommendation 7.6: Mainstreaming in the LSC

As part of its review of planning and funding of provision for disabled learners, from 2006 onwards, the LSC should aim to increase the proportion of disabled learners engaged in education and training at all levels. DfES to lead.

In order to achieve this aim, the LSC will have to ensure that disability issues are mainstreamed not only within the LSC, but also within its training providers. The LSC already has a responsibility to raise awareness of the DDA among its training providers, who are covered by the DDA legislation (via the Special Educational Needs and Disability Act 2001, SENDA), and therefore have a duty to make 'reasonable adjustments' for any disabled learners. The LSC has raised awareness of these duties through training courses and campaigns. Over the financial years 2003–4 and 2004–5 DfES provided funding for the LSC of £90m to improve disabled access to further education colleges and £40m to improve access to local education authority-run adult learning providers.

"Welfare to Workforce Development"

As part of the implementation of the Skills White Paper²⁸⁹, the National Employment Panel (NEP) examined measures to increase collaboration between the welfare

to work and workforce development systems, to ensure disadvantaged groups, including disabled people have the skills needed to succeed in the modern labour market.

The resulting report *Welfare to Workforce Development* contains recommendations to join up the employment and training systems and providers, with particular measures to improve the situation for disadvantaged people.

The report makes several recommendations that will improve the skills situation of disabled people.

- DfES and DWP to include in the mandatory work-focused interviews a joint programme to screen and train an increasing proportion of IB recipients.
- Information Advice and Guidance (IAG) contracts should give a priority service to Jobcentre Plus' clients lacking Level 2 qualifications, and focus IAG advice on the most efficient and effective route to employability.
- The necessary financial support should be in place to encourage Incapacity Benefit claimants to take up training as a route back to work.

Recommendation 7.7: "Welfare to Workforce Development"

This report endorses these recommendations, and recommends that they are implemented by the relevant

²⁸⁹ 21st century: Realising our Potential. July 2003

organisations as a matter of priority. 2005 onwards, with DWP in the lead.

New and developing skills initiatives

The Government is currently piloting/developing new skills initiatives. These are not aimed specifically at disabled people, but have the potential to increase the numbers of disabled people in work dramatically:

New Deal for Skills: NDfS is intended to focus on the low skilled, and will build on the entitlement of everyone to receive free training up to Level 2. Employers will be offered better advice and more flexible support to meet skills needs, along with free and flexible training for low-skilled workers participating in Employer Training Pilots (see below). The focus on basic skills will be particularly relevant to a large proportion of disabled people. They could particularly benefit from the proposed skills coaching service, which is intended to provide more intensive individualised support to help people secure the skills and training they need to gain sustainable productive employment.

Employer Training Pilots: ETPs are employer driven, with employers identifying basic and vocational skills gaps which affect their productivity. Employers will be reimbursed for giving low-skilled employees paid time off work to take education and training courses, up to Level 2. The Pilots have been

popular, but their effectiveness for disabled people could be improved. Whilst the majority of learners in the ETPs are working towards NVQ Level 2, disabled learners are more likely to be working towards basic skills.

Apprenticeships : On 10 May 2004 new Apprenticeships were announced, to replace the current Modern Apprenticeships (MA). These reforms are intended to involve greater numbers of employers, and open up apprenticeships to a greater number of people, extending provision to young people from age 14 and removing the upper age limit – previously MA's were only available to 16-to 25-year-olds. Rates for participation by disabled people in Foundation Apprenticeships (12%) are comparable with other cohorts, but not for Advanced Modern Apprenticeships, where it is significantly lower (5%). Despite this shortfall, the new Apprenticeships do not have a specific aim to increase the number of disabled participants.

**Recommendation 7.8a:
New Deal for Skills and Employer
Training Pilots**

DWP and DfES to ensure, from 2005 onwards, that the New Deal for Skills and Employer Training Pilots meet the needs of disabled people.

Recommendation 7.8b: Employer Training Pilots and Apprenticeships

From 2005, DfES to carry out further evaluation work to understand in more depth why disabled people appear to fare less well in the Employer Training Pilots and work with the LSC on impact measures for starts, completions, and employment outcomes of disabled people in Apprenticeships.

Advice and guidance must be accessible and high quality

The provision of good quality advice and guidance to disabled people is very important, particularly because many disabled people are not aware of the funding and assistance available to them for training. Information, Advice and Guidance (IAG) partnerships provide free services for all people over 19 to assist them in accessing or progressing in learning. A recent NEP report on skills provision found the quality of IAG services to be extremely patchy and even where effective, are under utilised. As explained in Chapter 6, Connexions also has a requirement under Section 140 of the Learning and Skills Act (2000) to co-ordinate the transition provision of disabled young people – but Connexions does not have the capacity to fully carry out this role.

Recommendation 7.9: Connexions and IAG

Connexions and IAG partnerships should have the ability to provide specialist advice to disabled people, either by making sure that their mainstream advisors have the right skills, or through specialist advisers for disabled people.

- Connexions and IAG to review how well their services meet the needs of disabled people.
- Connexions and IAG to make disabled people a target group for their services.
- Connexions and IAG advisers to have disability awareness training.

DfES to lead, from 2005 onwards.

Access to equipment and support in work is crucial

Access to Work (AtW) currently provides financial assistance towards the extra costs of employing someone with a disability. It is available to unemployed, employed and self-employed people and can apply to any paid job: full-time, part-time, permanent or temporary.

Box 7.4: Access to Work

An established public programme operating throughout Great Britain since 1994, AtW is designed for people with long-term health problems

or impairment who need extra practical support to take up work or do their job. The aim of the programme is to reduce inequalities between disabled and non-disabled people in the workplace by removing the practical barriers to work.

Types of support include:

- a **communicator at a job interview** for people who are deaf or have a hearing impairment;
- a **reader at work** for someone who is blind or has a visual impairment;
- a **support worker** if someone needs practical help because of their disability either at work or getting to work;
- **travel to work** element will pay up to 100% of the approved cost of a vehicle, or adaptations to a vehicle, or help towards taxi fares or other transport costs if someone cannot use public transport to get to work because of their impairment.
- **equipment or alterations to equipment** necessary because of individual disability; and
- **alterations to premises** or working environment necessary because of a person's impairment or the barriers they face.

The funding available depends on the employment status of the disabled individual at the time of application. For:

- **unemployed people starting a job and all self-employed people** – the programme will pay up to 100% of all approved costs;
- **people changing jobs** – the programme will pay for up to 100% of all approved costs; and
- **employed people who have been with the employer for six weeks or longer** – AtW pays the entire cost of support workers or those involving help with travelling costs. For adaptations to premises and equipment and special aids and equipment, and only for the sub-set of applicants who have been with their current employer for more than six weeks and are not self employed, AtW will not make any contribution to costs below £300. Above this sum, the programme will pay 80% of the costs up to £10,000 and up to 100% of the costs above £10,000.

Recent evidence has shown a positive feedback from AtW users. More than nine out of ten users said that AtW met their requirements completely or mostly and almost half of users said they could not work without it²⁹⁰. Employers value grants from AtW towards expensive

²⁹⁰ Thornton, P., Hirst, M., Arksey, H. and Tremlett, N. (2001) Users' views of AtW: Final Report of a study for the employment service. Research & Development Report ESR72, Employment Service: Sheffield.

IT equipment that involves upgrading costs, and having the costs of support workers met – especially where the costs of making an alternation to the premises or of providing on-going human support on the job are substantial and the employer is unwilling or unable to pay.

Evidence shows that grants under the programme can act as an incentive to hire a disabled person or retain an employee who becomes disabled²⁹¹. But where an employee needs special aids and equipment to continue to do the job, availability of grants under the programme does not appear to be a strong factor in retention of the employee²⁹². Almost half of employers believed their employee would be in the job without AtW²⁹³. However, feedback from employers suggests the financial contribution is important for SMEs.

Some organisations lack expertise in finding the right solution for an employee, and they valued this aspect of AtW. But anecdotal evidence suggests that in some cases specialist assessors also lack the skills to do proper assessments and users are persuaded to accept very expensive equipment which

is not necessarily the best value of money for them.

There also appears to be some confusion over the ownership of equipment. A survey showed that one in three employers did not know who owned it and a third of Disability Employment Advisers (DEAs) also felt employers were unsure about ownership responsibilities. However, very few employers had any concerns about ownership or purchasing. Where equipment does not belong to individuals, this makes it difficult for them to move jobs²⁹⁴.

Although opinions varied, the main areas users identified for improvement were:

- the time taken for special equipment and workplace alterations to be provided;
- follow-up by AtW staff once the support is in place;
- more promotion of the programme; and
- fuller information about the range of options available through AtW²⁹⁵.

Consultations with disabled people and employers have re-iterated the

²⁹¹ Thornton, P. (2003) What works and looking ahead – UK policies and practices facilitating employment of disabled people, SPRU.

²⁹² Thornton (2003).

²⁹³ Thornton, P. and Corden, A. (2002) Evaluating the Impact of AtW: A Case Study Approach, Research & Development Report.

²⁹⁴ Hillage J, Williams M, Pollard E. (1998) Evaluation of AtW, Employment Service Research Report

²⁹⁵ Thornton et al (2001)

need for the above improvements in the programme. Employers are particularly concerned with the speed of the programme, many have complained of waits of six months or more for equipment and adjustments. This is too long for employers to wait for an employee to be able to do their job. Lack of awareness among smaller employers has also been highlighted as a problem, especially as it is smaller employers who are more likely to be concerned about the costs of adjustment when considering employing a disabled person.

**Recommendation 7.10:
In-work support through
Access to Work**

By 2010, DWP should restructure the ways of providing in-work support through AtW. The objective of the new system would be to offer a new personalised system of in-work support which is effective and targets the right people at the right time without any delays, and which aims to increase recruitment and retention rates of disabled people

In the short term:

- DWP to examine possible options for increasing the employer contribution threshold and uprating them annually; and
- DWP to evaluate the likely impact of restricting or removing the ability of central

government departments to make use of AtW funding for disabled employees – and to make any changes to AtW in the light of this evaluation. The public sector has a role in promoting employment opportunities for people who are currently socially excluded, in order to promote regeneration and social justice. On these grounds, there are strong arguments for requiring central government departments – and potentially the wider public sector, in due course – to make provision in their expenditure baselines for the costs of employing disabled employees. This would free up additional funds for use by small and medium-sized businesses. However, the practical implications of such a change need to be carefully assessed – there must be no negative impact (even if only short-term) on the employment prospects of disabled people. Government departments should also continue to have access to the advice provided by AtW advisors.

In the longer term:

- allocate ownership of personal equipment and services (such as human support and transport fares) provided by AtW, which are personal to disabled people, to disabled people themselves and separate these from those

equipment and services that are particular to the employer and attached to the workplace environment, to build on the existing option of “ownership” of travel to work and support worker costs under AtW;

- DWP to consider using Direct Payments to pay for the personal equipment and services described above, or attach the funding to the individual budgets described in Chapter 4, to encourage people to exercise choice and control;
- streamline, shorten and improve the process of assessment of employment needs
- DWP to consider allowing self-assessment, supported by an audit process, to ensure that users are given the best possible advice when purchasing equipment;
- link assessment with the main Jobcentre Plus contact at an appropriate stage (just before the person is ready to enter employment); and
- investigate the ways in which disabled people could own their assessment and enable a system of “passporting” where disabled people may transfer a generic assessment to the next job.

7.4 Connecting disabled people with work and in work support

Transition to employment is often perceived by disabled people as risky and complicated

Disabled people who have been away from the labour market for a long time may experience lack of motivation as well as lack of confidence. Any difficulties of finding a job can be made worse by complicated rules, lack of direction or negative attitudes. In addition many people feel that work might have a bad effect on their health, even though inactivity might be worse for their general well-being.

Disabled people’s static position in the labour market is apparent through their often unsuccessful transitions into and out of work. The average annual rate of disabled people making a transition into employment from economic inactivity is 4%. The equivalent figure for non-disabled people is six times higher²⁹⁶.

Evidence on why disabled people perceive the transition into employment to be risky and complicated is mostly anecdotal. However, the majority of disabled people this project consulted with identified five main reasons why they perceive the transition into employment being a risky and/or complicated process.

²⁹⁶ Burchardt, T (2003) “Being and becoming: social exclusion and the onset of disability”, ESRC Centre for Social Analysis of Social Exclusion, London School of Economics, Case Report 21, London

- i. *Incapacity Benefit claimants are afraid of benefit reviews* – claimants are wary that looking for work would trigger a benefit review, which in turn can deprive them from their benefit claiming status.
- ii. *Incapacity Benefit claimants are wary of the financial implications of leaving benefits* – financial incentives are still quite limited for a substantial proportion of the claimant population. In fact upon entering employment a significant number of disability benefit recipients experience a loss or no change of income. Very few of those working 16 hours a week experience gains of more than £40 a week²⁹⁷.
- iii. *There is limited awareness of the existing return to work “linking rules”* – claimants are wary of having to reclaim their whole benefits package, and possibly running into the same difficulties they had in securing it in the first place, if their job did not work out²⁹⁸. Even those who return to benefits using the “linking rules” have to have spent a further 28 weeks on benefit before the linking rules can apply again²⁹⁹.

Box 7.5: The linking rules for Incapacity Benefit

People who leave Incapacity Benefit, to move into full-time work or training are entitled to re-claim their old benefit, for the same health condition, at any time within 52 weeks of starting work or training. The advantage of this is that they are guaranteed to get back their old benefit on the same terms and at exactly the same rate as before.

Individuals must inform the Department for Work and Pensions (DWP) by telephone or in writing that they have started work within four weeks of coming off benefits. They will then receive a letter from DWP confirming when the 52-week period runs out.

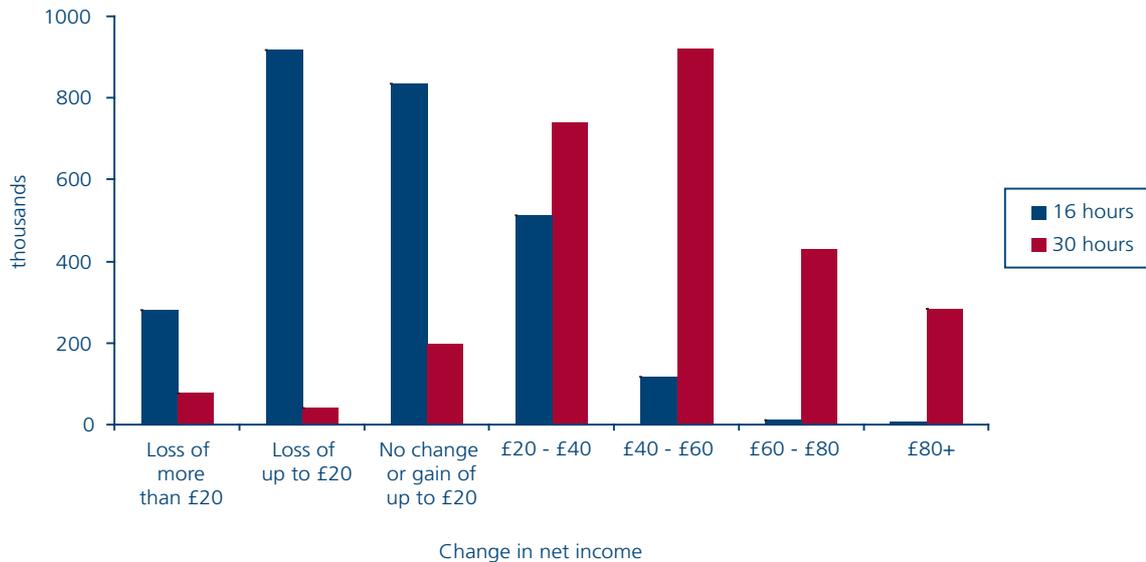
People may also be able to reclaim their old rate of IB within two years if they have been in receipt of Working Tax Credit or attending a training scheme for more than 16 hours a week. People who claim Housing (HB) benefit can reclaim HB within 12 weeks of leaving the benefit.

²⁹⁷ These calculations do not include Working Tax Credit and Return to Work Credit

²⁹⁸ From April 2004 people claiming IB and SDA will continue to claim HB and CTB for the first four weeks after starting work. This has been seen as a step in the right direction although improvements still remain to be made to improve the speed by which claims are processed.

²⁹⁹ Anecdotal evidence and evidence from our consultations suggest that many people have either no knowledge of the linking rules or do not understand them. In the case of HB, claimants have criticised the period of 12 weeks as being too short and expressed fears that delays in re-assessing benefit entitlement encourage a vicious circle of poverty as HB applicants struggle to make ends meet while re-assessment takes place.

Figure 7.2: Predicted gains to IRB* recipients entering work at 16 or 30 hours a week at £4.50, in 2004-5 (no working tax credit elements)¹



¹ Eligibility for Tax Credits would improve these outcomes

iv. *There is limited awareness of the financial incentives to return to work provided by tax credits – tax credits have a disability element that can improve the financial incentives for disabled people returning to work for 16 hours or more a week. However, awareness and take up among disabled people is low.*

v. *Permitted work rules for incapacity benefit claimants are restrictive – People claiming IS can work under permitted work rules for four hours at national minimum wage without having their claim reduced. They often wrongly assume that they are restricted to working only four hours or they are discouraged to increase their work hours if they*

know they will not gain more than £20 for up to 16 hours work – the point at which Working Tax Credit kicks in. This perceived gap between five and 16 hours has been repeatedly criticised as undermining the flexibility of the system and disadvantaging those with fluctuating conditions who may not be able to easily progress to 16 hours work after they pass the four-hour disregard mark.

Box 7.6: Permitted work rules

Permitted work rules describe the type of work an individual may undertake while on benefits. They aim to gradually bridge the gap between benefits and full-time work by allowing people to work up to 16 hours a week and still be on benefits.

Incapacity benefit claimants can try some paid work without the need for prior approval from a doctor. They can either work for earnings of up to and including £20 a week for an unlimited period or for 16 hours a week, on average, with earnings up to and including £72 a week for a 26-week period. This period can be extended for another 26 weeks if a Job Broker or Personal Adviser agrees that it will help a person's progress towards full-time employment.

Supported permitted work allows claimants to earn up to and including £72 per week for an indefinite period if they are receiving defined ongoing support or supervision.

Recommendation 7.11a: Linking rules and incentives to work

From 2006 Jobcentre Plus (with DWP in the lead) to provide better information and guidance to benefit claimants on the linking rules and existing financial incentives to return to work.

- Personal Advisers in Jobcentre Plus should be more proactive in delivering information and raising awareness about the flexibility of the current benefit system as a mechanism for improving transitions into employment

Recommendation 7.11b: Permitted work

In the light of recent evidence from the evaluation consortium and DEAC, DWP to deliver, in 2006, changes to the permitted work rules system, and also to further investigate the 5–16 hour issue.

There is a need for a personalised service of support, proactive job search and job-to-skill matching

Job retention rates are low for disabled people

Even allowing for the fact that some disabled people cannot or do not wish to move into employment, the proportion of non-disabled people likely to get work is still four times that of disabled people. Of those who take the big step and make a transition into work, one in three are out of a job again by the following year, compared with one-fifth of non-disabled people.³⁰⁰

Inability to retain a job however does not only happen when disabled people move back into employment after a spell of inactivity. There is also serious concern about job retention of people who become sick or disabled while in work. Survey data analysis³⁰¹ suggests that 80% of all those who become disabled are in employment at the time of onset, falling to 60% the following year and 36% the year after that.

³⁰⁰ Burchardt, T (2003)

³⁰¹ Bardasi, E, Jenkins, S and Rigg, J (2000) "Disability, work and income: a British perspective" Institute for Social and Economic Research Working Paper 2000-36, University of Essex

Disabled people are often not matched to the right job

Anecdotal evidence from the groups of disabled people this project consulted with suggests that some job brokers or advisers match disabled people to the first job available without any regard to their skills or previous experience. Those who are the furthest away from the labour market may need alternative work opportunities to help them move closer. However, many are provided with cycles of training which keep them further from the labour market and do not give them any relevant work skills. From the opposite perspective, Jobcentre Plus advisers feel that they lack the skills to address certain complex issues with their clients and are anxious about asking them questions on health conditions³⁰².

Evidence from New Deal for Disabled People (NDDP) evaluations suggests that the level of awareness of NDDP by members of the eligible population and employers is low. In addition, job brokers who were keen to meet their targets focused on the more work ready participants³⁰³.

Box 7.7: New Deal for Disabled People

The New Deal for Disabled People (NDDP) is the major employment programme available to people claiming incapacity-related benefits, and it is an important

part of the Government's welfare to work strategy. NDDP provides a national network of Job Brokers to help people with health conditions and disabilities move into sustained employment.

It is a voluntary programme that aims to help people on incapacity benefits move into sustained employment. It is delivered by around 60 Job Brokers, who are a mix of public, private, and voluntary sector organisations. Many provide services in partnership with other organisations. People wishing to participate in the programme must register with a Job Broker and have a choice over their Job Broker.

Additional funding of £30million in 2005–6 was announced in the PBR to ensure the continuation of the New Deal for Disabled People.

Job Brokers' links with prospective employers are often limited. Participants are sometimes critical of Job Brokers' perceived failure to deliver jobs to them. Some participants expected Job Brokers to have closer links with employers than many of them do in practice. They feel that these links must be strengthened.

³⁰² Thornton, P. (2003).

³⁰³ Corden, A., Sainsbury, R. and Thornton, P (2004). New Deal for Disabled People (NDDP): first synthesis report, No. 199, Department for Work and Pensions

Box 7.8: Case study of mismatching jobs and skills

Stephen was an IT manager for a big international company in the UK but left work because of depression. After being on benefits for five years, Stephen felt that he was ready to return to work and visited his local Jobcentre to discuss options with his disability employment adviser who then referred him to NDDP. The NDDP Job Broker suggested to him that he took up a job as a dishwasher. Stephen felt that his skills should enable him to at least try a job closer to his previous one but was not encouraged to do so or offered advice on how to go about it. He decided to stay on benefits.

A personalised case management approach should deliver better outcomes

Evidence from the US shows the importance of skilled case managers who can provide support, assist with tackling barriers and help participants gain access to the supports, additional help and job leads that are accessed through formal and informal networks. Intensive case management, personal goal development and support services had a significant impact on the subsequent earnings and employment of individuals who face multiple employment barriers³⁰⁴.

³⁰⁴ Finn, D and Simmonds D (2003) "Intermediate Labour Markets in Britain and an International Review of Transitional Employment Programmes" University of Portsmouth, Centre for Economic & Social Inclusion.

³⁰⁵ Weston, J, Jones, C and Stalker, K (2002) "Choosing, Getting and Keeping a Job: A Study of Supported Employment for People with Complex Needs", Scottish Human Service Trust.

Recent evidence indicates that advisers believe it essential to take time to build a picture of the individual's skills and interests, past experience, aspirations, likes and dislikes, and preferred areas and hours of work (vocational profiling) so that people could make informed choices³⁰⁵.

Box 7.9: Good practice example of a social enterprise – Breakthrough UK Ltd

Breakthrough UK Ltd is a social enterprise managed and run by a majority of disabled people; their main activities centre on training and employment support for disabled people in Manchester and Liverpool. Breakthrough UK Ltd supports disabled people towards independence, with a focus on working towards employment, and influencing policy and practice both locally and nationally. Their services provision and activities involve, employment support, work-related training and independent employment advocacy

Breakthrough UK Advisers' roles are to:

- receive referrals from Social Services, Jobcentre Plus, other agencies or self-referrals (30%);
- conduct an initial employment interview and put together a personal profile (including skill

assessment, agreeing goals and developing tailor-made training programmes);

- develop clients' job skills (update/develop C.V., complete application forms, write covering letters, conduct mock interviews and improve personal presentation);
- identify suitable vacancies (using existing employer contacts and current local labour market information or speculative approaches to companies);
- market client to employers (focusing on their strengths and support then through the recruitment process);
- provide planned follow up support to both client and employer; and
- "sign off" client as appropriate, but remain available.

This report supports the current Pathways to Work initiatives that should put in place an enhanced case management service for all people. Key roles for the case manager will include:

- conducting the assessment of need for services, providing support after the initial Jobcentre Plus contact and conducting further Work Focused Interviews;

- subject to evidence on its effectiveness, use the "screening tool" designed to identify those who do not need intensive case management because they are likely to move into employment in a short period of time;
- maintaining a long-term relationship with the client, building trust and paying attention to individual needs; and
- managing a personalised action plan, drawn up in partnership with the client and tailored to the client's needs, irrespective of circumstance.

Over time, it will be important that this work-focused case management role in Jobcentre Plus links up effectively with similar roles in other organisations (e.g. local authorities, CILs), in order to jointly promote support for independent living across disabled people's lives.

Recommendation 7.12: Job broker activity

By 2006, subject to resources, DWP should improve referral arrangements across to NDDP brokers, both via self-referral and Jobcentre Plus case managers. In addition the role of the Job broker should be developed to include:

- a clearer set of core activities;
- proactive job search;

- more accurate job matching to enhance retention; and
- better links with employers, but ensuring that vacancy filling is client led.

Disabled people must be empowered and well-supported in order to enhance their employability

By 2025 all disabled people who are able and willing to work should have the opportunity to get and retain employment, wherever feasible. This includes getting the right support from employers, health and social services, Jobcentre Plus and from all other relevant agencies and individuals.

Over three million disabled people are in work. But another three million are not in work. Of those who are economically inactive as a result of ill health or impairment:

- some will need little support to enter full-time employment;
- for some, full-time employment is likely to be an option in the near future with some additional support or some intermediate steps in part-time work or in education and training;

- some will be further from full-time employment or are unlikely to reach full-time employment at all and will require part-time or other types of employment and meaningful activity; and

- for a small minority no form of employment is ever likely to be practical³⁰⁶.

The Prime Minister said recently that the UK should aspire to increasing its employment rate from the current level of 75%, to around 80% of people in work³⁰⁷. This would mean over 1.5 million more people in work – and would certainly require a substantial increase in the number of disabled people in work, as part of the overall growth in employment. There is evidence³⁰⁸ to suggest that around one million disabled people who are out of work would like to work. Enabling these people to get into work would make a substantive contribution to achieving an overall employment rate of around 80%, and would significantly increase the current employment rate for disabled people, which stands at 50%³⁰⁹. Over time, there is not reason why even more disabled people should

³⁰⁶ Evidence suggests that many more of those people currently described as “difficult” cases would be able to find work or benefit from alternative activities.

³⁰⁷ Prime Minister’s Speech on the Opportunity Society, Beveridge Hall, University of London, 11th October 2004

³⁰⁸ Stanly K. and Regan S. (2004) *The Missing Million: Supporting disabled people into work*. Institute for Public Policy Research.

³⁰⁹ Other things being equal, supporting one million more disabled people into employment would increase the employment rate for disabled people to 65%. However, this employment rate is based on self-reported survey data, and it would be expected that people’s employment status might have some influence on their propensity to self-define as disabled. Hence the overall employment rate may be a misleading indicator of progress – though it remains a useful measure, and the 65% figure provides an important benchmark.

not be in work, particularly if the measures recommended in this report lead to more disabled people wanting to work. It will be important that the employment prospects of all disabled people are improved – not just those nearest to finding a job.

Helping people to gain and keep employment should be seen as a process of many parts where the individual is seen as moving along a continuum of training, work placements, voluntary work and open employment. To provide support more effectively and satisfy the needs of a diverse population a “menu driven” approach must be followed.

A menu of choices should involve³¹⁰:

- job search assistance and support (see recommendation 7.12);
- work-focused skills training;
- condition management programmes;
- work trials;
- work experience programmes;
- transitional employment placements;
- structured voluntary employment;
- in-work support; and
- open employment.

Clients who require support to enter the labour market would be able to choose in consultation with their case manager a range of elements from the above menu irrespective of the type of benefit they receive. Case managers should be able to propose the most appropriate type of support depending on the client’s needs and progress along his or her action plan.

The idea is that individuals would move along the continuum receiving progressively less support, as they become ready for each stage, ending in open employment. This continuum of support would be dynamic, person-centred and aimed at delivering services to disabled people in and on the route to employment effectively and promptly. The main advantage of this approach is that support would be tailored to individuals’ needs. Personalisation and flexibility of service would enable the individual to get the right support at the right time. Services would be provided both by voluntary, public and private sector to enhance the element of contestability and improve value for money.

DWP has published the “Building on New Deal (BOND)” paper to set out the Government’s strategy for the evolution of welfare to work policies. This report supports this initiative and supports also the Pathways to Work case management approach (discussed above), which is helping to promote a menu-based approach for supporting disabled

³¹⁰ This menu closely reflects the choices package available in the Pathways areas.

people into employment, Individuals consulted by the Strategy Unit identified the importance of personalised service and genuine choices as key to the success of a menu-based approach. More generally, a successful scheme will require:

- the existence of a clear and visible framework for support, publicised to disabled people and which enables them to understand the menu of options available to them and to make informed choices;
- clients will get access to services which are tailored to their particular personal needs;
- individuals to be offered opportunities for employment or rehabilitation from a menu of options depending on their circumstances;
- the action plan drafted with their case manager to be updated and followed along the way with clear milestones of progress marked;
- there must be justification of each training course, work placement, health intervention etc., to show how these choices fit with the client's needs and employment path; and
- alterations to the plan can take place as clients move through the continuum as their needs change.

There is some evidence on the benefits of supported employment schemes

Research has generally found that supported employment is a better financial option for disabled people than for those who earn sub-minimum wage in sheltered workshops. The cost-efficiency of workplace supports increases over time and becomes cost-efficient to taxpayers around the fourth year of operation. Even individuals with severe and multiple impairments are cost-efficient from the taxpayers' perspective³¹¹.

In the UK³¹² researchers estimated that for every £1 invested in supported employment, the taxpayer gets back around 43p from savings elsewhere in the system. As agencies become more experienced, the cost-benefit ratio improves. For agencies operating over five years the taxpayer recoups 54p in the £1 (in the US returns to the taxpayer tended to be higher).

Box 7.10: Supported employment

There is a range of models of employment support in England, including sheltered workshops, social firms, intermediate labour markets, supported employment and individual placement and support schemes. A cost-effectiveness study commissioned for the Social Exclusion Unit

³¹¹ Wehman, P and Revell, G (2003) "Lessons learned from provision and funding of employment services for the MR/DD population. Implications for assessing the adequacy of the SSA Ticket to Work". In *Paying for results in vocational rehabilitation*, editors Rupp, K and Bell, S, H, The Urban Institute.

³¹² O' Bryan, A, Simons, K, Beyer, S, and Grove B (2000) "A Framework for Supported Employment, Policy Consortium for supported employment".

concluded that supported employment and Individual Placement and Support projects were significantly more effective than other approaches in enabling people with mental health needs to find and keep open employment³¹³.

WORKSTEP is the current supported employment programme provided by Jobcentre Plus, with an emphasis on increasing the proportion of people who move from supported to mainstream employment. WORKSTEP provides support in jobs to disabled people who have more complex barriers to finding and keeping work but who, with the right support, are able to make a valuable contribution in their job and, where appropriate, develop and progress to open employment.

Around 26,000 disabled people are supported in work through the programme, either supported in jobs in the open labour market or in factories and businesses established to employ disabled people. WORKSTEP enables individuals to work effectively in a job by identifying their needs and providing the necessary support to fit their requirements. It offers a range of support to employers and employees and other practical help including, for example a job trainer or job coaching, mentoring

from colleagues, or advice and awareness support for to the employer and employees.

WORKSTEP follows an outcome-based funding approach to appropriate stages in the programme such as development planning, job entry and progression to unsupported employment. The programme continues to offer long term support in the workplace for those individuals who need it. Most providers offer substantial pre-employment support to ensure that individuals are working towards the right goal for them. There remains within the programme a need to continue to offer considerable support to some people to enable them to sustain employment.

A recent review of new WORKSTEP providers found that finding employers proved to be problematic for most, but not all, WORKSTEP providers. Those with good employer networks and skills in marketing clients to employers were the most successful. Differing emphasis was placed on delivering in-work support, ranging from full-time support on the job, and the promotion of workplace 'buddies', to job coaching in the early stages³¹⁴.

While progression to open employment is an outcome of the programme, concerns about

³¹³ Curran C, Knapp, M and Beecham, J, (2003) "Mental Health and Social Exclusion: Economic Aspects", Paper prepared for the Social Exclusion Unit by Personal Social Services Research Unit, London School of Economics and University of Kent at Canterbury

³¹⁴ Thornton, P., Banks, P., Riddell, S. and Beyer, S. (2004) A Study of Providers New to WORKSTEP, W195, Sheffield: Department for Work and Pensions.

meeting contract numbers meant that new providers did not prioritise this. Indeed, job starts tended to be considered the measure of success and progressions were seldom mentioned as an outcome. Claiming monthly payments was more profitable than claiming a progression payment, at least until contracted places had been filled³¹⁵.

**Recommendation 7.13:
Supported employment**

DWP should, from 2006 onwards, increase the flexibility of budgets within its current supported employment programmes away from programmes which fail to integrate disabled people in mainstream employment and into programmes which:

- assist disabled people progress towards open employment;
- provide value for money; and
- fulfil the wider objective of social inclusion for all disabled people.

This would imply reviewing the links of current supported employment strategy with needs provision and how resources are currently met by local authority social services departments.

7.5 Engaging employers³¹⁶

Employers often lack awareness about what it means to employ a disabled person

Employers can have negative attitudes towards disabled people

A recent survey found that only 62% and 37% of employers said they would take on a worker "with a physical or mental disability" respectively³¹⁷. Mental health is a particular concern for employers, often relating to interactions with colleagues and customers. Employers may also overestimate the costs of workplace adjustments needed to employ a disabled person³¹⁸.

Employers may not be aware of employees and potential employees' additional needs

Employers' attitudes are often perceived as a barrier by disabled people and may encourage non-disclosure of even a reluctance to apply for work. Evaluation of the NDDP³¹⁹ shows that often once a disabled person starts work, they no longer consider themselves to be disabled. Employers may then believe disabled people do not apply for their vacancies and that they do not employ any disabled people when this is not true.

³¹⁵ Thornton *et al* (2004).

³¹⁶ Recommendations in this section draw on the report of the NEP Employers' Working Group, which has advised this project.

³¹⁷ DWP research report 139 'Recruiting benefit claimants: A survey of employers in ONE pilot areas.'

³¹⁸ Remploy website.

³¹⁹ DWP research report 143 'Evaluation of the New Deal for Disabled People pilots'.

This may partially be due to the way employers think of disability. Often employers have a narrow view of disability, focusing on visible physical impairments, which they associate with incapacity to do things and extra costs³²⁰.

Employers' perceptions of the law on employing disabled people

Employers may not recruit disabled people due to fears about future risks of discrimination procedures. The DDA is considered to be much more effective in preventing discrimination for those in employment, rather than for disabled people applying for jobs. Just 9% of disability employment tribunal employment cases are based on recruitment, the remaining 91% are dismissal and reasonable adjustment cases. Employers may feel it is safer not to employ disabled people in the first place.

The employers' working group (see Annex B) has recommended that government publicity making a generic business case will not be effective in engaging the majority of employers. Employers are more likely to be interested in case studies of successful practice, and in advice from other employers, rather than messages from government.

DWP has recently set up an Employer Engagement Project, which is due to report by the end of 2005 on how government can better engage employers and encourage

and support then to recruit and retain more disabled people. The outcomes of this project will better inform government on how to take forward employer-employer awareness.

Recommendation 7.14: Employer awareness

Employers should lead a campaign promoting the business benefits of employing disabled people, to include case studies from different sectors and sizes of firms.

DWP and DTI should, from 2006 onwards, consider what role they should take in such a campaign in the light of the results from the DWP Employer Engagement Project. A successful campaign will also need the leadership of an organisation trusted by employers of different sizes and from all sectors; potential organisations include CBI, FSB and ACAS. The DRC would also need to be involved to ensure that issues relating to legal obligations and reasonable adjustments were adequately reflected.

Case studies would need to be a central part of the publicity, this would be particularly useful to allow (smaller) businesses to see how any barriers to recruiting disabled employees were overcome and where employers sought advice.

³²⁰ DWP research report 173 'Intermediate labour markets in Britain and an international review of transitional employment programmes'

As well as targeting employers and changing their attitudes, the general 'climate' and perceptions of disabled people by the general public are critically important. The media and advertisers have the power to make a real difference here. As disabled people become more represented in the mainstream media, and other walks of life (e.g. mainstream schools), this will have an effect on employers' attitudes and acceptance of disabled people in the workplace.

There is already some good progress in this area. The Broadcasting and Creative Industries Disability Network brings together the UK's major broadcasters to explore and address disability as it relates to the media industries. The Network makes it easier for members to recruit and retain disabled people and to promote and share best practice across the industry. The Government has also given OFCOM a specific responsibility to have regard to the needs of disabled people in carrying out their functions, and a duty to establish a committee to advise on the interests of disabled people. OFCOM also has a duty to promote the equalisation of opportunities for disabled people in relation to television and radio, and a corresponding duty is placed by them on broadcasters. The Government's "Images of Disability" initiative has had a major impact on advertising and on how disabled people are represented³²¹.

Despite progress, however, disabled people are still very under-represented in the mainstream media. There is a particular shortage of disabled people whose disability is 'incidental' to their role and disabled people in employment; there are still too many representations emphasising how 'different' disabled people are.

This report welcomes the progress made by some media organisations, especially broadcasters, to improve the media portrayal of disabled people, supported by better employment opportunities in media organisations, and the new duties placed on OFCOM. All media organisations are urged to examine their editorial and employment practices to ensure that they challenge prejudice and avoid reinforcing stereotypes.

Government as a major advertiser should continue to work towards a greater representation of disabled people, particularly in employment situations, in its non-disability specific material.

There is a lack of support available to employers recruiting and retaining disabled employees

At the recruitment stage and beyond, employers need advice and support on how to make any necessary adjustments. For example, 'DWP research into employers preparations for the October 2004 changes in the DDA found there was

³²¹ See www.disability.gov.uk/images_of_disability/.

a degree of uncertainty as to what constitutes 'best practice' in making adjustments and respondents reported that practical examples would be welcome³²².

Employers also have concerns about how to deal with situations that may arise when an employee becomes disabled or their impairment changes. This will be a particular concern for small employers who may not have previous experience of employing a disabled person. The lack of support and known sources of advice for employers has been highlighted as a major issue by the Employers' Working Group.

Some support to employers is currently available from a diverse range of sources. Examples include Access to Work which provides advice as well and financial help; Employers' Forum on Disability which runs an advice line for its members; and Business Link's website which provides advice on DDA and workplace adjustments.

There are also a large number of service providers working with employers to help them recruit and then retain disabled people, many of which are local small scale organisations. These vary a great deal in the service provided to employers. In addition to Breakthrough UK (Box 7.9), Papworth works with employers across eastern England to support them to retain staff becoming disabled (through its rehabilitation

programme), recruit disabled staff, and meet their skills requirements – as well as providing advice on the DDA.

While many of these sources of support and advice offer an effective service to employers, the sheer number of organisations, the variation in support provided along with difficulties employers face in finding out about these providers mean employers are not benefiting as much as they could.

Feedback from employers, shows that employers, especially SMEs, find the system difficult to navigate and do not have the expertise or the time necessary. In response to this, the Employers' Working Group sees a need for some form of brokerage to signpost employers to the relevant organisation or source of information they require in each situation that arises. The Group has suggested a web portal would be a cost effective way of providing this in a way that would be welcomed by employers.

**Recommendation 7.15:
Advice for employers.**

By 2006, DWP, DH and DTI should jointly consider how best to establish a single information point for employers. This will provide basic information on all aspects of recruiting and retaining disabled people and signpost organisations offering further support. Case studies based on

³²² DWP research report number 202 'Disability in the workplace: Employers' and service providers' responses to the Disability Discrimination'

successful practice by employers should also be included. The service would be further enhanced by a system of badging participating organisations, to ensure employers are referred to organisations providing high quality services.

Government should work with organisations such as CBI, ACAS and FSB to establish the most effective way of bringing together the wealth of information and advice available to employers and how this should be communicated to employers.

Links between Jobcentre Plus and employers

Jobcentre Plus has a new approach to engaging employers as customers of their recruitment services. This includes offering specialist advice on diversity issues including disability. To achieve maximum job placements for disadvantaged clients this is targeted on large employers.

Engaging SMEs represents a greater challenge. To engage SMEs, the Employers' Working Group has suggested that Jobcentre Plus needs to develop partnerships with organisations that SMEs are in more regular contact with. This would enable Jobcentre Plus to provide small businesses with practical advice regarding legal obligations and risks, and to market the assistance that Jobcentre Plus can provide with recruiting disabled

people. Research shows that SMEs' preferred sources of advice include accountants, banks and solicitors.

Recommendation 7.16: Jobcentre Plus and employers

Jobcentre Plus should develop, by 2008, 'reference sales' products regarding disability issues for use by SMEs' preferred commercial advisers and Business Links. DWP to lead.

There is currently a lack of effective incentives for employers to recruit and retain disabled people

The Employers' Working Group sees a need for an accreditation or award that employers want to have and that disabled people know identifies an employer with a commitment to and good record for employing disabled people.

The "two ticks" disability symbol aims to provide such an accreditation. The symbol is awarded to employers who are committed to offering interviews to all disabled applicants meeting the minimum criteria for the job. Other commitments are based on having procedures in place to recruit and retain disabled people. Feedback from disabled people and employers shows the symbol is not very effective. It is not valued and sought after by employers; is based on procedures rather than outcomes and disabled people are not influenced by seeing the symbol on job adverts.

It is recognised that an accreditation that involves monitoring of disabled employees will be difficult to implement – especially as many disabled people entering work may no longer consider themselves to be disabled, other disabled people may not want to tell their employer.

A good example of an accreditation valued by business is Investors in People (IiP) – the national standard which sets out a level of good practice for training and development of people to achieve business goals. The employers' working group has recommended that accreditation of IiP be linked to companies record on recruiting, retaining and developing disabled employees.

This report supports this as providing a genuine incentive to employers. IiP is reviewed every three years, with the latest review due to be completed shortly. Including specific requirements for companies to meet on their employment of disabled people as part of the criteria for being awarded IiP should be considered at the next review in 2007. An alternative would be the development of a good employers' standard – which would allow employers to demonstrate their achievements in terms of being good employers, of disabled people and other groups.

**Recommendation 7.17:
Investors in people and the
disability symbol**

- By 2007, subject to resources, DWP should review the effectiveness of the disability symbol, in consultation with business.
- Between 2005 and 2007, DfES and Investors in People should consider including employment of disabled people in their accreditation criteria and monitor it through their three year review process.
- Between 2005 and 2007, DTI should consider consulting businesses and trades unions on the potential development of an employment standard that encourages employers to introduce good employment practice, including the recruitment, management and development of disabled people.

Businesses may find further incentives to improve their recruitment and retention of disabled people from a commitment to publish information on their record, for example as part of their annual report. This would signal a commitment at board level which may be important in engaging staff throughout the organisation.

Government can lead the way as an exemplar employer

The upcoming public sector duty should be used to further involve local authorities and central government departments in the employment of disabled people. The public sector duty should encourage government to also become exemplar employers of disabled people.

Recommendation 7.18: Impact of the public sector duty

Government departments, government agencies and local authorities, from 2006 onwards as part of their public sector duty, should take the lead in demonstrating, promoting and reporting on best practice in the recruitment and retention of disabled people. The Employers' Working Group suggests that Jobcentre Plus could in particular play a leading role as an exemplar employer.

Box 7.11 Worcestershire County Council

Worcestershire County Council Social Services have established Employment Development Workers in some of their learning disability day centres. They develop vocational profiles with individual service users who want to work and then carry out a job search and match the person to an appropriate job vacancy.

They assist the disabled person throughout the interview and support them during the induction period. Job coaching is provided and regular contact is maintained for as long as it is needed. Concerns are dealt with quickly to ensure all parties are happy. The Employment Development Workers negotiate reasonable adjustments under the DDA and apply for Access to Work funding. For some disabled people the route to entering the labour market is a long and arduous journey and may take many years to achieve. However by building this function into day care provision, there is effective help for people who want to negotiate the route to employment.

7.7 Building information networks

Delivery of employment services is patchy and fragmented

A "mapping" study identified nearly 2,500 voluntary sector and local authority projects providing 6,700 pre-employment services to disabled people in Great Britain. 40% of these provided vocational training³²³. There are two important issues relating to the multiplicity of service provision.

- Available services may be unknown to individuals, their families, GPs or Jobcentre Plus advisers.

³²³ Arksey, H, Thornton, P and Williams, J (2002) "Mapping employment focused services for disabled people", Department for Work and Pensions, In-house report No 93.

- In the majority of cases, the projects have to piece together funding from a variety of sources and have to meet the demands of the funders. Continuity of funding under these circumstances is almost never guaranteed.

An additional problem is that projects can rarely afford external evaluation of their services. It is therefore difficult to get a comprehensive review of the effectiveness of these projects³²⁴. Lack of good quality evaluation of outcomes means it is difficult to provide evidence of what works. This impairs the dissemination of good practice and prevents policy makers rolling out what works on a wider scale.

The Directgov online programme has a vision to provide access to local information and all government public services. This would include disabled people. There are also currently plans in place by the eGovernment Unit and departments to investigate current online directories available for integration with Directgov.

Box 7.12: Evidence of good practice – Cheshire County Council Resource directory of available support for disabled people³²⁵

The new resource directory of available support was the result of co-operative joint work between 23 separate organisations in

Cheshire as part of the Joint Investment Plan by the Cheshire Welfare to Work Partnership.

The directory pulls together information of the services provided by a wide range of contributors from the voluntary sector, private sector, government agencies, local authorities etc. It has been difficult for advocates and the disabled people to access the right information regarding employment services for disabled people in their area and the information in this directory addresses this gap.

The directory has been arranged in sections depending on the type of support available, namely: Workstep programme providers, employment services and job centres, support available from Cheshire County Council, the voluntary sector, careers services, information advice and advocacy services, FE Colleges, health services and borough council services.

Recommendation 7.19: Online directory of services

By 2008, DWP to lead, with DfES and DH, to set up a joint initiative between the public, private and voluntary sector with an aim to create a national online directory of service providers by area, and

³²⁴ There have been some reviews of projects funded by European Union initiatives, such as HORIZON.

³²⁵ Source: http://www.cheshire.gov.uk/SOCIAL/adults/resource_dir/resource_dir.htm.

inform disabled people of the services offered to them. Links with Directgov and current online directories must be considered. This would be a separate initiative to complement the independent employers' advice source in recommendation 7.15.

The directory should be complemented with a national helpline, as joint initiative between DH and DWP, to provide information to disabled people and their carers and relatives.

Sharing information through local partnerships

Effective information sharing through local partnerships may also help achieve positive employment outcomes. This is demonstrated by an innovative scheme, operated by the employment charity Tomorrow's People, which helps disabled people to progress into work. The scheme involves placing employment advisors at GPs' surgeries to provide patients with a "one-stop-shop" for health and welfare advice in a bid to help sick and disabled people back to work. The employment adviser is present at the surgery one day a week and sees an average of five patients. The scheme has been a great success producing returns for both patients and doctors. From nearly 200 patients who have seen the adviser, 100% have returned to employment or are back in education or training. On average

75% are still in work 12 months on. In addition, the scheme has helped save an average of five consultations per patient, saving the surgery thousands of pounds.

Box 7.13: The Northern Way

The Northern Way is part of the ODPM's 'Creating Sustainable Communities' project and is being led by the three Northern Regional Development Agencies, covering the north's eight city regions. By collaborating with government and regional stakeholders, they have developed a long-term vision for helping the economy of the whole of the north to grow. The overall aim is to 'establish the north of England as an area of exceptional opportunity'³²⁶ through improving the local economy and quality of life.

One of their aims is to bring more people into work to increase output in the north (and close the output gap with the south). They will help companies create jobs (e.g. by improving transport links).

Given the high numbers on IB in the north (840,000 people), they have set a target of moving 100,000 from IB into work by 2011. To do this they will work with local RDAs, Jobcentre Plus and Regional Skills Partnerships.

³²⁶ Source 'The Northern Way: First Growth Strategy Report' (2004).

**Recommendation 7.20:
Employment advice**

DH and DWP – working with other government departments – should explore and test options for placing vocational advisers in healthcare and other settings. Testing from 2006, rollout from 2008.

The overall approach would be a multi-agency model of support and advice within healthcare settings and possibly other settings where there are disabled people without work or at risk of losing their job (e.g. children's centres, healthy living centres or other non-stigmatising community-based settings). These initiatives would test the economic, health and social benefits of vocational advice as a way of enabling people to achieve their full potential.

This would imply:

- providing a voluntary and confidential service, accessible by self-referral or referral by health professionals;
- focusing on providing advice and support with an aim to refer and move clients towards vocational opportunities (e.g. specialist or mainstream support services, supported or open employment) in the community; and

- developing a common evaluation framework and shared outcome measures.

A more comprehensive roll-out in 2007 and the development of national standards will take place after identifying what kind of advice works, for whom and why.

Chapter 8: Towards Improved Delivery

Summary

This chapter assesses what needs to be done to ensure effective delivery of the programme of reform set out in previous chapters. Particular attention is paid to the application of the public service reform agenda to services provided to disabled people.

There are six recommendations:

- The strategy for improving the life chances of disabled people should be developed fully and timetabled with milestones, communicated widely, and aimed at steady progressive reform to 2025.
- Provision for disabled people should be reviewed and a new mix of mainstream, specialist and integrated provision derived from the strategy described in Chapter 3.
- More coherent and explicit standards should be developed bringing legislation and other rights into a coherent framework.
- The review of provision should address ways of encouraging effective delivery of services that meet the needs of disabled people.
- A strong focus is required within government to make sure that priority is given to disability issues, and to provide oversight of a process to reform delivery in line with the public service reform agenda.
- New arrangements should be established for securing participation of disabled people in policy design and delivery at all levels.

This report aims to provide a basis for policies and services to improve the life chances of disabled people. It sets out a programme of sustained action towards attainment of the

vision and goals over the next 20 years. This requires a clear commitment to effective policy and support for disabled people, within which strategy, leadership, standards

and involvement of disabled people lead through into reformed provision and systems of delivery. After an introduction (8.1), the chapter considers:

- the characteristics of an effective delivery system, and how well current arrangements provide what is needed (8.2);
- proposals for change (8.3);
- providing leadership (8.4);
- involving disabled people (8.5); and
- anticipating risks (8.6).

8.1 Introduction

Despite much improvement in recent years, provision for disabled people remains characterised by:

- multiple agencies and services;
- a lack of clarity in resource allocation in relation to needs;
- a focus on processes rather than outcomes;
- invalid assumptions about the abilities of disabled people to be active citizens;
- delays in receiving provision;
- misperceptions and low expectations about what disabled people can do;
- low levels of awareness of the DDA;

- different assessment procedures;
- poor co-ordination;
- insufficient access to high-quality advice, information and advocacy; and
- limited accountability and management of performance.

There is a lack of pace and direction for reform, and little evidence that disabled people have yet benefited from the public service reform agenda. Without further change, current arrangements within government are incapable of addressing these constraints.

8.2 Characteristics of an effective delivery system for disability and an assessment of the current arrangements

A sound framework for delivering the recommendations in this report will derive from the vision, aims, and goals and ought to contain:

- an effective strategy: a planned way forward with targets and milestones;
- coherent provision: programmes, services, benefits, individual budgets and other support designed to deliver the strategy;
- clear standards: rules, codes of practice, legislation and guidance, and inspection;
- accountable leadership: from Government; and

- inclusive communication and participation: ensuring full involvement of disabled people and public awareness of the issues.

**An effective strategy:
a planned way forward with
targets and milestones**

Assessment of current arrangements

There is no explicit national strategy for improving the life chances of disabled people. Previous chapters reveal many real problems.

- A lack of shared understanding and accountability has led to inadequate action to remove barriers to disabled people's inclusion. This is reflected in major policy initiatives that fail to address how disabled people can best participate.
- A fragmented approach, with services being provided by different organisations in ways that do not co-ordinate to maximise the life chances for disabled people.
- Failure to include disabled people effectively in the workforce, resulting in a loss to society of the contribution that disabled people could make; and too many people out of work, with high costs being imposed on the benefits system.
- Outdated attitudes that make invalid assumptions and act to exclude disabled people, for example, by presuming that people with learning difficulties cannot be parents.

- A lack of focus upon outcomes and a continuing reliance on process leading to unnecessary bureaucracy.

*Characteristics of an
effective strategy*

The strategy set out in Chapter 3 and expanded in Chapters 4–7 is the bedrock of an effective delivery system. If it is to lead to effective delivery, the strategy needs to:

- set out the territory for which leadership, planning, resources and dedicated services are required;
- give focus and structure to a sustained reform process;
- give disabled people a clear idea of their rights and what support they can and should expect;
- facilitate policies and programmes that relate to the “whole person”;
- drive out the diseconomies which result from silo working; and
- highlight disability within policy on diversity and mainstream programmes.

The strategy set by this project will need to evolve over time, setting an ongoing series of objectives and milestones that will ensure effective and sustained delivery. This will enable central and local policy makers to plan, incentivise and measure progress towards the strategy, and the vision, aims and

policy goals behind it. Flexibility will be needed to head off emerging risks (see section 8.6), and build upon new economic, social and political opportunities.

Coherent provision: programmes, services, benefits, individual budgets and other support designed to deliver the strategy

Assessment of current arrangements

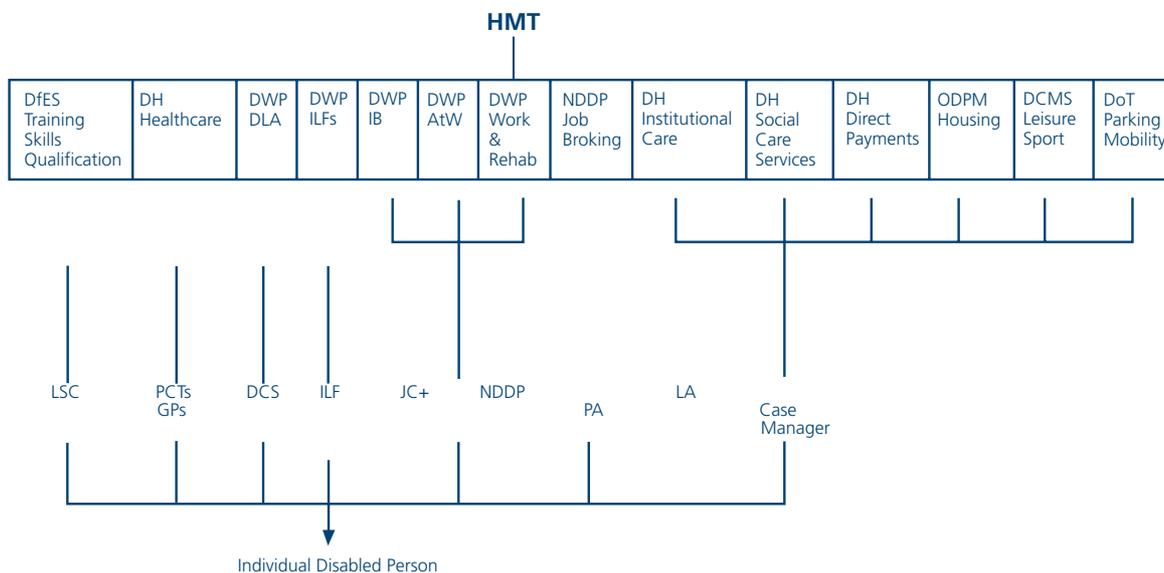
There are two fundamental problems deriving from the lack of an overall strategy and policy framework for improving the life chances of disabled people.

- A large number of different services, payments, tax credits, and support schemes for disabled people, designed and delivered as by-products of other policies and programmes, with little

coherence. This is not a person-centred system.

- No carefully judged balance between mainstream, specialist and integrated provision. Mainstream programmes frequently fail to take the needs of disabled people into account. Specialist programmes often only exist because of that failure, and consequently are designed narrowly – and as the chart below reveals, are delivered by a variety of Departments with different and unrelated definitions of client, rules, and assessment arrangements. Integrated programmes aimed at meeting the needs of disabled people in the round, or when they make significant life transitions, are rarely contemplated, let alone proposed and tested for cost effectiveness and conformity with public service reform.

Figure 8.1 Major government structures providing disability service arrangements



Box 8.1: Case study on lack of incentives for joint-working

Helping IB clients back to work is a major government priority for Jobcentre Plus, which it carries out through interviews and supported job search. But success depends critically upon addressing people's health needs, the ability of clients to live independently in the community, and basic transport. Yet policy and delivery arrangements on health and social care support, and on transport issues, are determined separately from policy towards employment-related support, which leads to separate programmes delivered in isolation from Jobcentre Plus services, suggesting potential for savings as well as benefits to disabled people.

Disabled individuals, especially those accessing multiple services, want the support and services which they need to be drawn together – whether about health, employment, care needs, housing, access to amenities, or parenting. Integrated programmes will not always be a cost-effective response, and it is not always practical for all support to come through a single gateway. But wherever possible, and without breaching confidentiality, there should be some consolidation of separate assessment processes, gateways, organisations, case/care managers and application forms that disabled people have to deal with simply on account of their impairment or ill health. Not all people will have the same needs, but should be able to select from a common menu.

Characteristics of effective provision

Well designed and effective provision for disabled people will conform with the principles of public service reform.

- Increased voice, choice, personalised services and local accountability.
- High standards of service delivery with strong leadership and incentives that reinforce delivery on the vision.
- Clear roles for all partners national and local.

With this in mind, effective provision will be characterised by conformity with the three key policy principles discussed in Chapter 3 – inclusive, effective and informed. For these principles to be delivered, government will need to:

Design inclusive systems – coherent provision will involve:

- systems including disabled people through active removal of attitudinal, physical and social barriers;
- ensuring that disabled people's needs are met through mainstream provision wherever possible, with full consideration

of the barriers to be removed, requirements for accessibility, and additional/specialist support where required;

- introducing new integrated programmes;
- less bureaucratic services with short lines of accountability, few intermediaries, and value added at each level;
- contestability, carefully designed to secure challenge, but with the necessary collaboration for best value to customers; and
- sharing of best practice and ways of achieving better outcomes.

Ensure high performance – coherent provision will involve:

- strong leadership and a tight performance regime with clear goals, standards, targets and monitoring to ensure sufficient consistency between individuals, over time and between localities and services in line with the recommendations;
- provision based on evidence of what works and evaluated pilots where necessary;
- ensuring the quality of specialist provision which personalises services to the individual with careful consideration of the appropriate methods between cash, services and programmes;

- joint working between providers becoming the norm, not the exception, in addressing and overcoming conflicting policies;
- staff skilled developed and motivated to deliver the outcomes, with full support from key stakeholders and an informed public;
- local empowerment for flexible modes of delivery for improved outcomes, with the ability to connect resources to meet individual needs;
- an emphasis on personalised responses which enable choice and empowerment; and
- avoiding differences in approach which prevent successful transitions.

Empower people – coherent provision will involve:

- disabled people (and their families) systematically involved at an individual and policy-making level – at local authority, regional and national levels – to inform how policy and standards are designed and delivered – and in development of their own organisations such as Centres for Independent Living;
- addressing access needs, including independent advocacy, providing support (for example payment of fees and expenses) and a

framework for disabled people and their families to be involved ensuring that they are empowered to have their voice heard and that their voice carries weight; and

- support in the form that people want and need, with avenues for redress when things go wrong.

Clear standards: rules, codes of practice, legislation, and inspection

Assessment of the current arrangements

There is currently a fragmented approach, with many unrelated standards.

- Overarching this whole agenda are the Disability Discrimination Act and the new Disability Discrimination Bill, and these will be underpinned by codes of practice published by the Disability Rights Commission. But this is not easily related to other standards.
- The standards – and therefore training – of many professionals are insufficiently broad to incorporate knowledge of related disciplines to help and refer people and facilitate person-centred support.
- In housing, Lifetime Homes standards are not sufficiently adopted.
- NSFs for Long term Conditions, Mental Health, Older People and Children have considerable potential and set out national

standards in each of these areas, but doubts remain about enforceability and their ability to make a difference.

- There is no NSF for disabled people, nor widely accepted standards for key topics such as Independent Living and for disability equality training. The “two ticks” symbol for employers covers only recruitment.
- Information about the performance of services is not generally made available to the people who use those services.

Overall, the various sets of standards do not connect and relate to each other, making it difficult to determine the overall quality of the support that disabled people receive.

Box 8.2: Standards for independent advocacy

Standards in this growth area are a mix of legal and voluntary, aspirational and minimum. They include the Advocacy Charter, the Advocacy Safeguards Agency in Scotland, DH Standards for children’s advocacy services, the Complaints Advocacy Service standards, standards for mental health services users, and Kings Fund standards for health and social care for BME communities.

Characteristics of effective standards

Effective standards need to:

- be meaningful and understood;
- guarantee minimum quality of provision;
- challenge organisational performance;
- be practical and enforceable; and
- leave room for local flexibility.

The basic ingredients of the current system will need to remain in place, but will need to have a clearer sense of purpose within the overall framework for delivering improved services to disabled people.

- Legislation should provide the essential framework of civil rights.
- Professional standards for individuals and performance standards for delivery agencies should ensure that all disabled people are clear about the help they can expect.
- Employment standards should be a driver of improvements in recruitment and retention, adaptations and workplace attitudes.
- Accessibility standards should be comprehensive across all barriers
- Information about whether standards are achieved should be made available to disabled people.

There should be visible coherence across standards, with consistent definitions across age groups, with careful inspection of performance against them and audits of service delivery. Future legislative opportunities should be considered as part of an overall programme of disability reform, with civil rights as a component of effective support for disabled people.

Accountable leadership: from government*Assessment of current arrangements*

There is no central focus currently providing effective leadership on disability issues.

The role of the Minister for Disabled People is generally associated with responsibilities within DWP around legislation and benefits. And many disability issues are managed as subsets of other departmental business, so that budgets and PSA targets for disability issues are sought and agreed within the SR process with limited coherence or relationship either to each other, or with any relationship to an overall policy framework for disability. This makes subsequent downstream joining up the only possible response, which may well be hard and expensive to achieve.

There are inter-departmental forums capable of promoting a disability agenda, but these are reactive, meet infrequently, and do not command action or commit resources.

Characteristics of effective leadership

Achieving the strategy and securing public service reform will require a strong focus in government to lead and manage policy towards disabled people and to oversee its delivery. Such a focus would be required to:

- develop, implement, review and improve the strategy;
- promote the vision and priority status for disability issues;
- draw government departments together at both ministerial and official levels, and achieve coherence with devolved administrations;
- maintain pressure for change across government, and ensure action to meet the goals and milestones;
- facilitate initiatives, consider the development of future targets, spending plans and bids for resources for disability through the Spending Review process;
- support alignment of main-stream and disability-specific programmes;
- secure research, and collect and disseminate data on disability;
- include disabled people and secure effective communication with and information flow to disabled people, supporting and empowering them to take responsibilities and ownership;
- have a complementary relationship with the government machinery for diversity and oversight of the Commission of Equality and Human Rights especially throughout the five-year period of special treatment for disability, and before any review of the current discrimination legislation framework;
- be owned by departments not in rivalry with them, and be resourced for the long haul subject to continuing to demonstrate added value;
- bring together the different stakeholders needed to secure progress;
- have a degree of distinctiveness, charisma and authority to secure positive and popular impact with the media and public; and
- have the power to challenge diseconomies resulting from responsibilities divided between departments.

Box 8.3: Leadership on disability, leadership on diversity

Over the next few years there will be enhanced attention to diversity and human rights issues, with the advent of the CEHR and the possibility of a review of the current discrimination legislation framework. There will be opportunities for progress on disability to be assisted through diversity-orientated programmes

(for example in seeking commitment from employers) and similarly for progress on diversity to be driven from the base of disability programmes. It will be important for there to be effective relations between the central focus in government for disability and that for diversity issues to review and take advantage of such opportunities.

Inclusive communication and participation: ensuring full involvement of disabled people and public awareness of the issues

Assessment of current arrangements

Disability groups and individuals are not well represented within policy development, despite devices specific to particular policy areas such as DPTAC for transport and DEAC for employment. Relations between disabled people's organisations and government, while improving, have been tentative and partial. Differences of opinion persist between organisations of and for disabled people, and for different impairments, dissipating energies and impact. There is not yet a strong trust between government and disability organisations, nor between many of the disability organisations. And there are often misunderstandings and disagreements about what is meant by disability.

Characteristics of an effective system

- Well-developed local and national capacity is needed in disabled people's organisations and formal links and agreements with key organisations including local authorities and central government.
- National minimum standards to make sure disabled people are not out of pocket or otherwise penalised for participating.
- Disabled people's organisations become part of the contracting culture involved in both monitoring and delivering key services.
- Disabled people can choose the level at which they are comfortable to participate.
- "Nothing about us without us" is a guiding principle in policy and service delivery.
- Disabled people are not fearful of the consequences of getting involved.
- People's access needs are addressed as a matter of routine.
- Independent advocacy is available to support disabled people's participation.
- The public sector duty to promote equality of opportunity leads to a process of front-end assessment of policies that involves disabled people.

8.3 Proposals for Change

This chapter makes six recommendations that together provide the components of an improved delivery system for disability issues:

- The strategy for improving the life chances of disabled people should be fully developed and timetabled with milestones, communicated widely, and aimed at steady progressive reform to 2025.
- Provision for disabled people should be reviewed and a new mix of mainstream, specialist and integrated provision derived from the strategy described in Chapter three.
- More coherent and explicit standards should be developed bringing legislation and other rights into a coherent framework.
- The review of provision should address ways of incentivising effective delivery of services which meet the needs of disabled people.
- A strong focus is required within government to ensure that priority is given to disability issues, and to provide oversight of a process to reform delivery in line with the public service reform agenda.

- New arrangements should be established for securing participation of disabled people in policy design and delivery at all levels.

This section examines ways of making delivery work more effectively, and sets out the reasoning behind our recommendations. The next section looks at securing a focus for effective leadership.

Recommendation 8.1: An evolving strategy

The strategy for improving the life chances of disabled people should be fully developed and timetabled with milestones, communicated widely, and aimed at steady progressive reform to 2025.

Government departments to lead, supported by the ODI. Initial activity in 2006, then ongoing.

This report's proposed strategy is described in Chapter 3 and expanded in Chapters 4 to 7. For the purposes of sustained delivery the strategy will need to be kept "live" and up to date, communicated effectively to all players to motivate and drive progress over time, expressed sufficiently clearly and explicitly to enable disability issues to be reviewed across the piece, and with regular reporting on progress to the Prime Minister.

Recommendation 8.2: A review of provision

Provision for disabled people should be reviewed and a new mix of mainstream, specialist and integrated provision derived from the strategy described in Chapter 3.

Government departments to lead, supported by the ODI. Initial activity in 2006, then ongoing.

The existence of a single strategy permits a **thorough review of activity** that supports the strategy. A robust review process, carefully scheduled to address the full range of opportunities – and which looks openly at all forms of provision against all levels of need – is required. Policy makers need to maximise cost effectiveness by targeting as broad a group of disabled people as possible within a range from complex to simple needs, so that all those who need support and can benefit from it are included. Specialist programmes for disabled people, together with appropriate mainstream programmes, need to be carefully reviewed against the criteria outlined in this chapter. The SEU will shortly be looking at how best to improve delivery of mainstream services to disadvantaged adults, including a specific focus upon people with disabilities and chronic health problems, which will provide valuable input to the review work recommended here.

The review will provide the opportunity to consider completely **new forms of integrated, person-centred provision** that will:

- be in the interests of public service reform and cost effectiveness;
- better meet the transition needs identified, whether from childhood to adulthood, between services, into independent living, or into retirement; and
- support both individuals and families.

It will need to identify best ways of structuring planning and establishing such person-centred provision, including who delivers, how to pilot, staff training and competencies, incentive regimes, and inspection.

The existence of a policy framework also permits a **review of priorities**. For example:

- movement of resources out of institutional and segregated care, day-care and repeat special courses into mainstream programmes;
- disabled people working in partnership with statutory organisations to shape services and contracting processes that ensure good participation is widely and appropriately practiced;
- provision of independent advocacy, key worker roles and service navigation/brokerage;

- extension of rights to communication support; and
- employing more occupational therapists and physiotherapists.

Integrated person-centred provision may be **achieved in different ways** depending on the scale, degree of personalisation and permanence of change required, and recognising the different albeit overlapping needs of different service users. The options for moving towards “single front doors” for disabled people are, in ascending order of revision and change:

- departments and local delivery agencies would simply make sure that they have a basic knowledge and awareness of each other’s activities in order to help clients to navigate the different systems;
- departments might bid to HMT for financial resources for their own programmes as now, but jointly develop (with their delivery agencies) common principles and guidance for pooling or sharing of funds and for harmonised delivery by the different delivery agencies;
- departments might act as above but also cream off a percentage to create a top-up fund at national or regional level to meet additional and unexpected needs;
- departments collude to make a common bid for one budget held centrally, but which is then allocated to delivery agencies

partly in relation to past needs but partly revised for a better balance; and

- the central budget is used to fund a single programme run by one agency for one department, with appropriate influence from all departments.

Recommendation 8.3: Standards

More coherent and explicit standards should be developed bringing legislation and other rights into a coherent framework.

Government departments to lead, supported by the ODI. Initial activity in 2006, then ongoing.

This report proposes that there should be reviews of existing standards and the way in which they fit together. This will include standards for workforce planning, professional training, competence, and qualifications for service providers and other professionals working in support of or otherwise impacting on the lives of disabled people. Effective means for inspection and assessment against these standards should be developed. These reviews should take place as part of an ongoing process of improving the quality of services.

There may be opportunities to improve the consistency of definitions of disability for example to ensure equity at tribunals, and to

reconcile definitions within social care legislation with those in the DDA. The Public Sector Duty will make a vital contribution to the introduction of a clearer framework of standards and expectations. Beyond the current Disability Bill there may be an opportunity to review the current discrimination legislation framework, and for further legislation around welfare reform. Any further legislation should be considered against the overall strategy and in particular the coherence of standards for disability across the board.

**Recommendation 8.4:
Incentives for effective delivery**

The review of provision should address ways of incentivising effective delivery of services which meet the needs of disabled people.

Government Departments to lead, supported by the ODI. Initial activity in 2006, then ongoing.

Earlier chapters have addressed the on-the-ground delivery of services for disabled people. **Local authorities** will frequently be at the centre of local delivery arrangements. The review of provision needs to look carefully at the appropriate mechanisms for ensuring effective delivery of services and support by local authorities and by other delivery agents. There are a number of options.

- **Investment:** Significant additional resources for disability will not be available in the short term. But a case for additional resources where appropriate should be built for the longer term, starting in Spending Review 2006.
- **Incentives:** This report recommends that work should be carried out to bring together the evidence base about disabled people's outcomes into a small number of key outcomes which can be incorporated into the national incentive structure. These incentives could be in the form of a refined DWP PSA target or through existing departmental PSA targets when these are re-negotiated in Spending Review 2006.

However, there is a limit to what national targets can and should achieve. The primary focus should be on locally generated targets based around existing performance measures. So, for example, local disability targets could be devised for key Best Value Performance Indicators, on which all authorities would be required to report in their annual Performance Plans.

Furthermore, the increasing emphasis on user-focus and diversity in the national CPA framework is welcomed as a way of ensuring that councils take seriously the need to provide appropriately-tailored services to all members of their communities. Local PSA targets with

local performance frameworks to which service users contribute will be increasingly important. The targets set will need to be stretching, with full local commitment secured. Over time local organisations of disabled people should become involved in target setting and inspection, becoming resourced and skilled to do so. For all local targets, joint performance measures should be considered because of the potential of these to deliver more effective joint working.

There will need to be new ways of drawing support together at local level, and for generating proposals for joint arrangements to operate at regional and national levels. Local Strategic Partnerships (LSPs) will be a powerful means of joining up local service deliverers and encouraging innovative approaches to new person centred provision, involving disabled people in the design. Given their rationalised funding streams and extra freedoms and flexibilities, Local Area Agreements (LAAs) may offer added scope in this respect, initially in the 21 pilot areas and then in a potential wider roll out from 2006/7. And there needs to be closer day-to-day working between partners such as PCTs and local authorities. Workforce planning is also needed to make sure that the required skills are in place in sufficient quantity. And there will be an increasingly important role for Government Offices.

Standards and duties:

Recommendation 8.3 argued for a review of standards. The proposed public sector duty will also need to be built into inspection regimes, and will provide a basis to tighten expectations and to review progress. The Disability Rights Commission will produce guidance on evidence gathering, involvement of disabled people and how to assess impact.

8.4 Providing Leadership

A central theme of this chapter is that strong leadership will be needed to make a real difference to the lives of disabled people.

Recommendation 8.5: Government leadership of reform

A strong focus is required within government to ensure that priority is given to disability issues, and to provide oversight of a process to reform delivery in line with the public service reform agenda.

Government departments to lead, supported by the ODI. Initial activity in 2006, then ongoing.

Stronger leadership – meeting the criteria set out in “characteristics of effective leadership” in section 8.2 – might, in principle, be secured by changed procedures and incentives, new mechanisms, or structural change.

- **Procedures and incentives**
These could include ideas such as an action plan based on the

strategy, single Spending Review bids, PSA targets, requirements on departments and delivery agencies to report on progress, points and reward systems on front-line staff. However it is difficult to envisage these being activated successfully within existing departmental arrangements and responsibilities without imposing an unacceptably high additional level of coordination and oversight from central departments.

- **Temporary Mechanisms**

There is some attraction in regarding the challenge as a one-off step change best addressed by introducing new thinking and energy from disabled people themselves and the private sector working in collaboration with government officials. Options might include a task force and a 'tsar'. Both of these mechanisms have been used elsewhere in government and abroad with varying success.

This report sees few attractions to either of these approaches as the primary way forward. The task is long term and will need sustained attention, and temporary arrangements cannot bring about the necessary realignment of policy design and delivery management. However the report recommends that in recognition of the especially challenging nature of the issue, a **Task Force for Independent Living** be established, consisting of ministers and officials from central and local government

working with organisations of disabled people to develop imaginative new solutions across the health /social care/ employment/housing interfaces. The Task Force would help to develop thinking on independent living and on individualised budgets.

- **Structural Change**

There are a number of options other than leaving things as they are. These include increasing the powers of the DRC, creating formal bilateral links between government departments, or creating a new Diversity Unit. This report has concluded that a structural step change is a necessary precondition for the degree of sustained cross government working implicit in the strategy.

This report therefore sees the most promising way forward as being to create a new **Office for Disability Issues** (ODI) which would support improved arrangements for securing collaboration between ministers and officials, and for involvement of disabled people themselves. It would also build strongly upon the foundations of existing departmental responsibilities.

The ODI will be a new slim strategic unit, with few executive functions and with an essentially coordinating role, providing direct support through its chief officer to the Minister for Disabled People. It would provide a focus within

government for disability as a discrete subject and be the means by which departments collectively drive forward the strategy. The ODI will be “owned” by the leading departments (DH, DWP, DfES, ODPM and DfT) who would between them plan and steer its work programme and ensure that this fits well with the Government’s wider equality agenda. The Office will cover people of all ages, support the Minister for Disabled People in a full cross-government role, and provide a broader context for relevant government departments to develop policy. The dynamic focus created will enable departments to take their emerging thinking into a collective process within the ODI and to pursue coordinated policy development as well as planning and monitoring changes to the delivery system for disability, with direct involvement from stakeholder groups. They will thus be able to assure ministers that policies are compatible and coherent. Using the ODI should become a natural way of doing business.

Individual departments will retain responsibilities for policy and programmes for disabled people. Any new programmes developed under the auspices of the ODI would generally be delivered by departments and not by the ODI. Departments would be responsible for preparing annual report on the strategy, which could potentially be combined with reports on the public sector duty. Figure 8.2 is an

illustrative example of how the Office for Disability Issues, once operational, could act across government on policy design and oversight of delivery. This illustration suggests a potential outline role of the Office, rather than a full or final description.

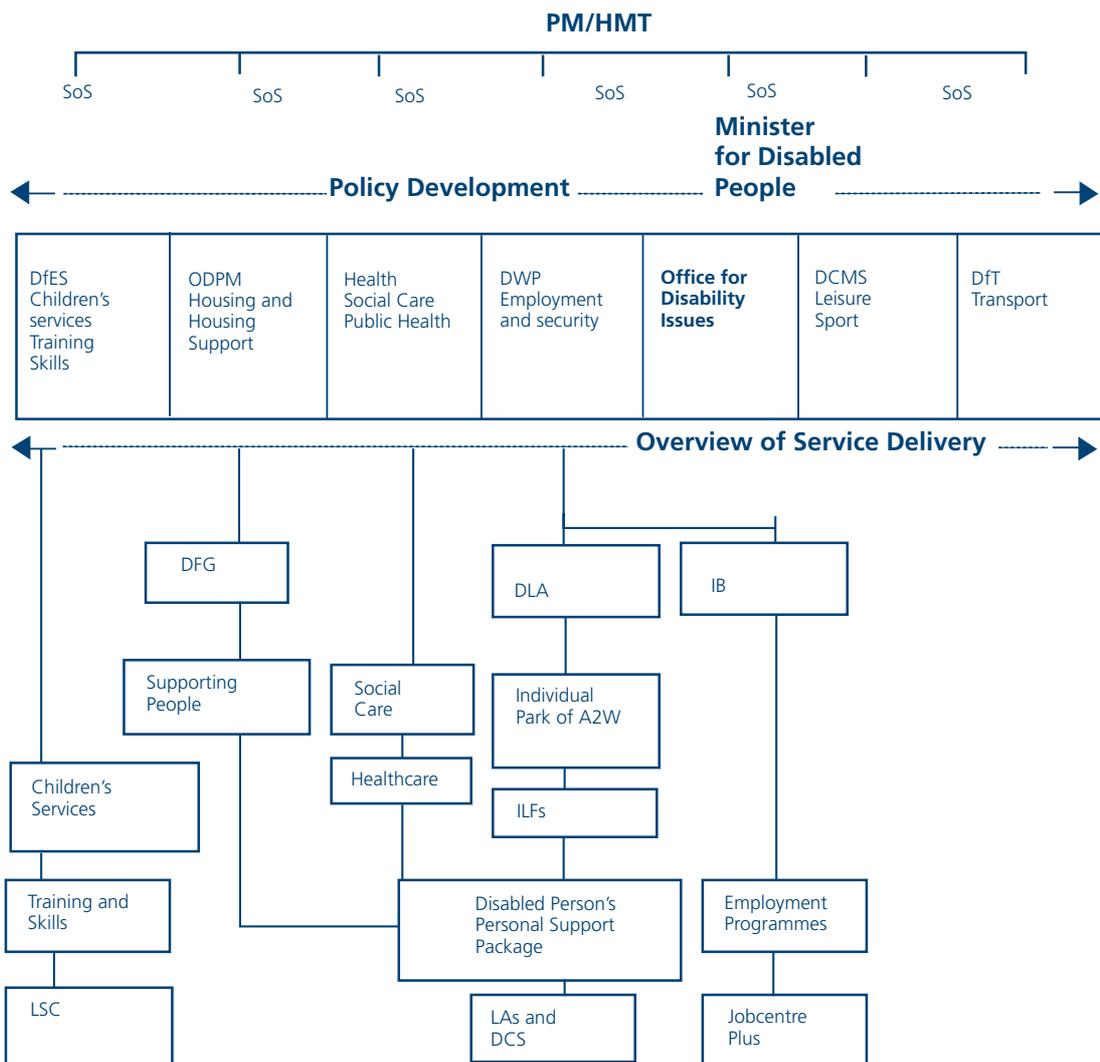
There is merit in starting with a restricted range of functions and staffing, allowing departments collectively, following appropriate consultation with disabled people and other stakeholders, to establish the remit of the ODI before building up to “full capacity”. A staged approach to establishing the ODI is set out in Chapter 9 of this report. Government will need to consider if any of the DWP’s current functions in relation to disability (civil rights, analysis, targets, legislation, oversight of the DRC and disability benefits policy) should transfer to the ODI in due course.

The ODI should be established as a discrete cross-government unit within the DWP group. But given the crucial links into the work of other departments the status of the Office should be kept under review by ministers, in the light of its contribution and the success of the strategy it is tasked with coordinating. One key role will be for the ODI to act as an exemplar for the rest of government in the way in which it does business, by ensuring that its activities are fully inclusive and accessible.

A ministerial cross government group on disability should be established to lead and sustain the reform process and in particular to ensure that collective responsibility translates into shared commitment of effort and resources to ensure that all Government Departments are accountable for the success of the change process.

A cross-government group of senior officials should be established with the task of establishing the policy framework and driving through changes to the delivery system. It should have particular responsibility for assembling the resources required to complete the establishment of the ODI, and acting after that as the “board of

Figure 8.2 Illustrative outline of how the Office for Disability Issues might work across Government



management” for the ODI. It will take ownership of the strategy, identify what pace of reform is possible within available resources, set key milestones, and advise ministers on the appropriate build up of functions for the ODI.

This report does not recommend that any of these disability specific arrangements be combined with other diversity responsibilities. There is a very significant agenda here to pursue, and existing arrangements will ensure that disability develops appropriately as part of the wider diversity and equality agenda, including the development of the CEHR.

Box 8.4: A comparison with New Zealand and South Africa

Both New Zealand and South Africa have world leading arrangements that are strongly welcomed by disabled people and effectively recognise the cross-cutting nature of the problem and its solution. They have each developed a social model based national strategy jointly with disabled people’s organisations that applies across government. Both countries also have a small central unit dedicated to supporting all government departments to implement the strategy and monitor progress. The strategy is given clout either through legislation as in New Zealand, or placement in the very centre of government as in South Africa. In both countries there is

active championing by senior ministers. The emphases on government wide responsibility, partnership with disabled people, monitoring and active follow-up are particularly important lessons.

The Scottish Executive, the National Assembly for Wales and the Northern Ireland Office should be invited to consider to what extent it would be desirable and appropriate for them to join in with these new arrangements, or set up partnership arrangements, in order to share best practice and maximise consistency across the UK.

8.5 Communication and Involving Disabled people

Recommendation 8.6: Participation

New arrangements should be established for securing participation of disabled people in policy design and delivery at all levels.

Government departments to lead, supported by the ODI. Initial activity in 2006, then ongoing.

This report has highlighted the importance of involving disabled people and their representative organisations in policy design and delivery. The criteria for reform should, if properly applied, make sure that disabled people contribute at both national and local level to policy development and the delivery of all provision affecting them.

The public sector duty will require a significant increase in the involvement of disabled people within key public sector bodies.

Box 8.5: The details matter – and unless disabled people are involved, there can be unintended negative consequences.

One example is the installation of road humps that have been shown to be an inexpensive way to increase children’s safety. Road humps have been put in with good intentions. However they cause some disabled people (and those with temporary injury) extreme pain stopping them accessing medical treatment, working, visiting friends and family. In Harlow a disabled person was unable to visit their dying parent to say goodbye owing to road humps. There are other road calming measures that can be used in most circumstances that will allow these disabled people to access their environment and participate in society.

User involvement protocols should be drawn up and implemented at all levels. And this report also recommends the establishment of a **National Forum for Organisations of Disabled People**, chaired by the Minister, through which disabled people can meet and contribute to policy development. This would provide a direct signal to disabled people that their contribution is essential to delivering the new strategy, would overcome a degree

of current uncertainty about inclusion of disabled people in policy development, and would provide an example for similar arrangements associated with delivery of services. There will always be a risk that the organisations wish to make faster progress than proves to be possible. But it would formalise current tentative arrangements and bring in valuable input.

There must be a sustained effort to build up the **capacity of organisations** representing disabled people and their ability to work together and with other partners. Government contracts have the potential to assist this process.

There will need to be a stronger long term programme for handling cultural change and the media, and a **public dialogue** about building a society that includes disabled people, similarly to changes in attitudes secured by feminist and gay pride movements.

8.6 Anticipating what might change

An important aspect of planning for effective delivery is to review where new developments might affect delivery of the strategy, whether positively or negatively. There are a number of possibilities, including:

- progress in medical technology and genetics;
- changing household and family structures;

- changes to rules on human fertilisation;
 - influence of celebrity role models;
 - severe increase in obesity and physical inactivity;
 - increased complexity of impairments;
 - landmark legal judgements;
 - economic fluctuations and recession;
 - immigration;
 - changes to law on euthanasia; or
 - workforce crises in health, social care or employment.
- practice, costs and benefits of policy options, and to mitigate the risks to the strategy from technological, social, medical and legal developments.

The Office for Disability Issues will need to coordinate systematic analysis of risks and opportunities, with departments leading work relevant to their responsibilities, retaining research capacity and factoring findings into reviews of performance against the strategy and amending the strategy as necessary.

The ODI might also usefully establish, possibly through a long duration contract with one or more HE institutions, a capacity for intelligence, information and evidence collection and analysis, and for information and data sharing around sound disability equality

Chapter 9: Implementation

Summary

All government departments will be responsible for driving forward the strategy and the practical measures identified in this report – all of which have been accepted by the Government. The Office for Disability Issues will help to coordinate policy across government.

This chapter proposes early action to move forward on the recommendations by ensuring that all parties know what is expected of them by when, and that there is a positive climate and context for reforms to take root. Effective implementation requires five elements to be in place:

- immediate impact;
- a clear and understood challenge;
- clarity of roles;
- achieving and sustaining momentum; and
- resources lined up.

Each of these is examined in turn, concentrating on immediate action in the early months but recognising also the need to sustain focus on reform after that.

9.1 Immediate impact

The publication of this report signifies that:

- the Government has accepted the recommendations, and all directly concerned ministers have signed up to the relevant proposals, conclusions and an effective
- Ministers and officials have accepted the remit set out for the establishment of the Office for Disability Issues. The Office's terms of reference will be developed in conjunction with all government

ongoing process of reform over the coming months and years;

departments, as work to establish the ODI gets underway in accordance with the timetable in Section 9.4; and

- the Strategy Unit has discussed with officials across government – especially those expected to contribute to the nucleus of the ODI – the steps that need to be taken to implement this report’s recommendations, and mechanisms are in place to take these forward.

The Strategy Unit has also sought to make sure that major organisations representing disabled people – along with employer organisations, trade unions and voluntary organisations – have all been involved in identifying the right way forward to supporting disabled people to help themselves, and in improving their life chances.

9.2 A clear and understood challenge

The messages of this report will be communicated to the many partners and individuals who will be involved – directly or indirectly – in its implementation. The focus will be on the first half of 2005, but will be an ongoing process.

This report has been published in a range of accessible formats, and feedback invited. Lead departments will be responsible for consulting on specific policy changes as they are taken forward.

The contents of the report will be further disseminated through upcoming conferences and seminars. Opportunities will be taken – by ministers and officials – to speak at events organised by external stakeholders. And where there are perceived to be gaps, government will work with external stakeholders to plan and hold additional events. These will cover the report as a whole and also specific key issues of rehabilitation, equality awareness, capacity building and independent living, issues where early significant change is required. They would aim to communicate the case for reform and to involve stakeholders in the implementation process.

A wider campaign of awareness-raising will be launched, tying in with the opportunities presented by other initiatives such as the Disability Discrimination Bill. The aim will be to inform the public about the central messages of disabled people’s inclusion and why that is not yet happening. This will highlight the way that disabled people can be unintentionally rendered dependent through the various barriers discussed in this report, and the need to consider the rights of disabled people to live independently with full opportunities to improve their quality of life.

9.3 Clarity of roles

All government departments will be responsible for taking forward the strategy for change initiated in this report. Clarity about the different roles will need to be achieved quickly if early progress is to be made. The table at the end of this chapter lists all the recommendations from the chapters of this report and assigns responsibilities.

Central departments – No10, the Treasury and the Cabinet Office – will have a vital role in ensuring that the full Government commitment demonstrated by the publication of this report remains strongly evident, and that departments’ commitments – to the strategy, the reform programme, and to establishing the ODI as an effective cross-government institution – are sustained.

Lead responsibility in government for implementation of the report will rest with the Minister for Disabled People. The Minister for Children, Young People and Families at DfES leads all government work on children and families, and will make sure that all elements of this report with implications for children and families are implemented. Implementation of the report will be championed at Cabinet level by the Secretary of State for Work and Pensions, coordinating a process through which departmental Secretaries of State report progress annually to the Prime Minister on

both implementation of the strategy and delivery of the public sector duty.

Lead responsibility for overall coordination of the process of implementation, including building upon reactions to the published report, will fall initially to the DWP Director for Disability, who currently supports the Minister for Disabled People and whose command will undertake the preparatory work for the launch of the ODI.

The Strategy Unit will manage the process of receiving feedback and resolving uncertainties around specific recommendations, and will liaise with DWP to make sure that all helpful ideas are fed into the implementation process.

DWP will need to verify ministers and senior officials with national responsibilities for disability issues in each department, who will collectively form the inter-departmental ministerial and officials’ groups. DWP will ensure that these groups are established under the chairmanship of the Minister for Disabled People and the DWP Director respectively, and that they accept collective responsibility for progressing the implementation of the report’s recommendations and for staffing the ODI.

DWP will establish liaison with the Devolved Administrations with a view to engaging them in appropriate ways with the strategy

and reform process. It will also be important to ensure opportunities for discussion with key partners and stakeholders who were involved with the project to make sure that they are clear about their roles and remits, with joint events to resolve any uncertainties and boundary issues. These groups should include organisations of and for disabled people, family and carer organisations, education, health and leisure bodies, inspectorates and academics working in this field.

9.4 Achieving and sustaining momentum

As the essential conditions for success are established through the steps outlined in Sections 9.2 and 9.3, new institutional arrangements will be put in place and steps taken to plan effectively for the achievement of the report's recommendations. The strategy laid down by this report will need to be carefully developed to include detailed responsibilities on departments and agencies, and with milestones finalised for both separate goals and for overall progress.

The Strategy Unit anticipates that the sequence for introducing the immediate new institutional arrangements will be:

- inter-departmental officials' group – by March 2005;
- ministerial group – by March 2005;

- the ODI – launched by September 2005 (but see below);
- National Forum of Organisations of Disabled People – by September 2005; and
- Task force for Independent Living – by December 2005.

The establishment of the ODI needs to be given particular attention. It can be secured without legislation or major resource switches or additions, and that in turn will make possible most of the other reforms. However there will need to be careful judgment about the balance between putting this in place quickly to show progress, and taking the time to get the right structure. The ODI must also be seen as a means of facilitating progress, not distracting from it.

The timetable for the four stage process identified in Chapter 8 should be as follows:

Stage One: DWP-led work with other departments to put in place the ministerial and officials groups and the other institutional changes and to co-ordinate planning towards the establishment of the ODI – from January 2005.

Stage Two: Launch of ODI following arrival of dedicated staff from departments, and operating core functions of establishing committee secretariats, liaison with Scotland and Wales, strategic planning for pursuit of the strategy and priority recommendations, engaging with

stakeholders, ensuring that the new institutional arrangements are working effectively, and planning how to approach SR2006 – by September 2005.

Stage Three: the ODI progressively takes on additional coordinating and cross-cutting functions subject to resource availability. These functions would be additional to activities already established by departments, and would potentially include: planning the reviews of provision, mainstreaming, standards and inspection, development of targets and spending requirements, establishing working agreements with the Diversity Unit and the CEHR, implementing the annual reporting process, developing models for funding and contracting, examining performance management and incentives, promoting awareness, and developing a capacity for intelligence and data sharing – by September 2006.

Stage Four: Reviewing and modifying arrangements with experience: an opportunity to reflect upon progress being made and consider changes to the remit in the light of (a) the emerging roles of the CEHR; (b) the relative attraction of adding into the ODI the DWP functions of legislation, civil rights, oversight of the DRC, analysis and possibly DLA strategy; and (c) the relative success of joint-working – by September 2007.

Beyond institutional change, and assisted by the existence of new machinery, sound planning will be required to secure practical commitment to changes in delivery, such as reviewing programme structures, and introducing new approaches to independent living, preparing for SR2006, and developing PSA targets that reflect the evidence base on disabled people's outcomes. There will need to be a realistic and achievable schedule for moving forward on the recommendations, established by each individual department working with the ODI. Relevant criteria will include:

- each department's resource baseline and pressures;
- fit with existing PSA and other top priorities;
- fit with current change programmes;
- available staff and financial resources;
- invest-to-save opportunities;
- relations with main stakeholders;
- political and media sensitivities; and
- technical feasibility of proposed changes.

The inter-departmental officials' group should receive proposals from the ODI for a considered programme

of implementation of this report's recommendations addressing both immediate and longer-term reforms, progress on which will remain the responsibility of each department, and which take account of the circumstances of individual departments. Once the officials' group is content the programme should be put to the ministerial group for endorsement. This is an iterative process whereby performance in one time period will inform progress in the next time period.

Any impact secured by the publication of the project will be hard to sustain against competing issues, and it is therefore vital to make some significant early changes with a life of their own before resources and political interest move inevitably on to other things.

Looking ahead, this report envisages a staged approach to overall implementation.

- In the short term, the focus will be on making effective use of existing resources, and on building a robust evidence base and consensus for the way forward.
- In the light of this evidence base, options should be considered for a coherent package of pilots and new approaches, for which funding could potentially be sought in Spending Review 2006.
- In the longer-term, and subject to evaluation of the evidence and to

the availability of resources, successful approaches should be introduced at national level.

9.5 Measuring success

Implementation of the package of measures set out in this report should:

- increase disabled people's ability to live independently – to enjoy the same choice, control and freedom as any other citizen – at home, at work, and as members of the community;
- enable young disabled children and their families to enjoy 'ordinary' lives, through access to childcare, early education and early family support to enable them to care for their child effectively and remain socially and economically included;
- support disabled young people and their families through the transition to adulthood. Transition will be better planned around the needs of the individuals and service delivery will be smooth across the transition; and
- increase the number of disabled people in employment while providing support and security for those unable to work.

It will be important to develop specific indicators of progress to measure whether these outcomes have been achieved. These indicators should be outcome-based

and should not add undue burdens in terms of data collection. Government departments should be responsible for reporting on each of the indicators relevant to their recommendations through the annual reporting process. These indicators should be developed through consultation with relevant bodies including local authorities.

**Recommendation 9.1:
Developing measurables**

From 2005, ODI, with support from other Government departments, to develop specific, outcome-based indicators to enable progress on the recommendations in this report to be measured.

However this report constructs a case for persuasive bids to be put forward within SR2006, provided that the evidence is assembled and arrangements for effective delivery are in place. With the 20 year time horizon of the vision it will not be credible for the recommendations to be challenged on the grounds of available resources, only on timescales.

9.6 Resources lined up

Beyond a small commitment of staff resource, the early stages of implementation are not dependent upon additional resources in the SR2004 period. The institutional changes and other measures can be driven through in this period provided that departments operate with a degree of flexibility within existing allocations of staff and cash – which is why their commitment is so central. To the extent that this report's recommendations have new resource implications, they will in the main have to be timed to fit with windows of opportunity for new bids and allocations, in Pre-Budget Reports, Budgets and Spending Reviews.

Summary of recommendations for quick reference

This list provides short summaries of each of the recommendations contained in the main report. It is important to note that the recommendations in the main report text are the agreed versions for implementation; this summary table is for quick reference only.

'Lead responsibility' shows the government department accountable for initiating action. Where the Office for Disability Issues (ODI) is shown, DWP will lead as necessary until the ODI is established. Implementation of the recommendations is subject to future decisions about resource allocation.

Summary of recommendations	Lead responsibility	In support	By when
Chapter 4: Independent Living			
(4.1) Modelling good practice Government departments should model good practice in involving disabled people.	Government departments	ODI	2005 onwards
(4.2) User involvement protocols should be developed by public bodies, in consultation with disabled people.	Government departments/ service providers	ODI	By 2006
(4.3) User-led organisations Each locality should have a user-led organisation modelled on existing CILs.	DH and ODPM		By 2010
(4.4) Supporting independent living Work towards a new approach that delivers support, equipment and/or adaptations according to the principles set out on page 77.	DH	DWP, DfES, ODPM	By 2012
(4.5) Piloting individualised budgets Develop an evidence base for individual budgets which bring together sources of funding, services, equipment and adaptations.	DH	DWP, ODPM	Early 2005 onwards
(4.6) The role of local authorities Local authorities should have a key strategic role in delivering the new system	ODPM	DH	2005 onwards

Summary of recommendations	Lead responsibility	In support	By when
(4.7) Information and advice DH should assess existing information and advice provision and consider an SR06 bid to address any gaps.	DH		By 2006
(4.8) Supporting disabled people to help themselves DH should: a) introduce, after consultation, a more appropriate definition of 'disabled person' for community care services; b) consult on merits of a 'right to request' not to live in a residential or nursing care setting; c) analyse costs and benefits of amending charging policies for residential care; d) consider an 'invest-to-save' SR06 case for community-based resources for those otherwise placed in residential care	DH		a) As soon as possible b) In 2005 c) By end 2006 d) By 2006
(4.9) Improving the DFG ODPM should consider reform to the DFG in the light of the forthcoming review.	ODPM		By 2005
(4.10) Including disabled people in housing initiatives ODPM should work with organisations of disabled people and others to ensure housing initiatives include disabled people.	ODPM		2005 onwards
(4.11) Lifetime Homes Review the effect of the 1999 guidance on access to dwellings, and consider the feasibility of incorporating Lifetime Homes standards into Building Regulations.	ODPM		By 2006
(4.12) Transport and independent living Encourage local authorities to include transport and mobility needs of disabled people in assessments within the new system of individualised budgets	DH		2005 onwards

Summary of recommendations	Lead responsibility	In support	By when
(4.13) Transport and local authorities Encourage local authorities to play a strategic role to ensure that disabled people do not experience barriers on journeys.	DfT		2005 onwards
Chapter 5: Early Years and Family Support			
(5.1) Individualised budgets Individualised budgets should, in principle, be extended to families with disabled children.	DH	DfES, DWP, ODPM	By 2012
(5.2) Childcare and early education a) All 3-4 year old disabled children should have access the free part-time early education provision and providers will have access to a fully-support early years SENCO. b) Families with a disabled child under 5 years to be able to access high quality, flexible childcare. c) Extension of 'wraparound' care to be fully accessible to disabled children over 5 years.	a) DfES b) Sure Start Unit c) DfES		a) By 2010 b) By 2015 c) As this is rolled out.
(5.3) Evaluation of children's services a) National evaluations of children's services to assess impacts on families with disabled children. b) Guidance should be issued on local and regional evaluations of children's services to ensure they take account of the needs of disabled children.	a) DfES b) DH and DfES		a) 2005 onwards b) 2005 onwards
(5.4) Keyworkers a) Provision of a keyworker to families should be considered as a key performance indicator. b) Children's Trusts should ensure that all families have access to clear information about local support.	a) DfES and DH b) DfES		a) 2006 onwards b) 2006 onwards

Summary of recommendations	Lead responsibility	In support	By when
(5.5) Early intervention Phase one: Identify mechanisms that enable local authorities to switch spend from later intervention to early intervention. Phase two: Depending on Phase one outcomes, assess the case for an invest-to-save pilot for early intervention.	DfES	DH	1) By 2006 with follow up studies. 2) 2006 onwards
(5.6) Equipment a) Assess whether community services are able to deliver the NSF recommendation on children's equipment, and, if not, make recommendations for improvement. b) Equipment services should be considered as a key performance indicator of council social care and education services.	a) DH b) DfES and DH		a) By 2006 b) 2006 onwards
(5.7) Housing Recommendation 4.9 should also apply to families with disabled children and disabled parents.	ODPM	DfES	By 2005
(5.8) Workforce The children's workforce should be capable of meeting the needs of disabled children.	DfES	DH	Incorporate into current work
(5.9) Children's Trusts Local authorities, PCTs and Children's Trusts should work together and with partners to commission services for all disabled children.	DfES and DH		Incorporate into current work
(5.10) Joint Area Reviews Consider how disabled children can be reflected in the Joint Area Reviews of children's services and in the CPA.	DfES and DH		2006 onwards
(5.11) Data collection and information sharing a) Coordinate basic data on the number and needs of disabled children in local areas.	a) DfES and DH		a) 2005 onwards

Summary of recommendations	Lead responsibility	In support	By when
<p>b) Include disabled children in the Children Act databases.</p> <p>c) Include disabled children in the Common Assessment Framework.</p>	<p>b) DfES and DH</p> <p>c) DfES and DH</p>		<p>b) Incorporate into current work</p> <p>c) Incorporate into current work</p>
Chapter 6: Transition to Adulthood			
<p>(6.1) Continuity in delivery from child and adult services</p> <p>a) Different models of multi-agency transition should be evaluated and disseminated.</p> <p>b) Children's Trusts should be encouraged to work as necessary with young disabled people up to the age of 25.</p> <p>c) Pilots should assess how individualised budgets could cover the transition period.</p>	<p>a) DfES</p> <p>b) DfES</p> <p>c) DH</p>	<p>c) DWP, DfES, ODPM</p>	<p>a) By 2006</p> <p>b) 2005 onwards</p> <p>c) By 2012</p>
<p>(6.2) Adult programmes extend self-directed control to young people when they are ready</p> <p>a) Collate and disseminate good practice examples, including Expert Patient model.</p> <p>b) Investigate how ICES initiatives can ensure they include children and young people.</p> <p>c) Support for young people developing individual budget plans (as per recommendation 4.3)</p>	<p>a) DH</p> <p>b) DH</p>		<p>a) By 2006</p> <p>b) By 2006</p>
<p>(6.3) "Universal" services assessed on meeting the needs of disabled young people and their families</p> <p>Facilitating evaluation of new model of service delivery through better evidence via the new public sector duty, improving collection of information, better inspections, and clearer performance indicators, and targets.</p>	<p>a) All government departments</p> <p>b) DRC</p> <p>c) DWP</p> <p>d) Ofsted and Healthcare commission</p> <p>e) DfES</p> <p>f) DfES</p>	<p>e) DH and DCMS</p>	<p>c) 2006/7 and ongoing</p> <p>e) By 2006</p>

Summary of recommendations	Lead responsibility	In support	By when
<p>(6.4) Family support that bridges transition</p> <p>a) Review remit of Family Fund Trust.</p> <p>b) Individualised budgets (as per recommendation 6.1) should support young people and their families across transition.</p>	<p>a) DfES</p> <p>b) DH</p>	<p>a) Family Fund</p> <p>b) DWP, DfES, ODPM</p>	<p>a) By 2006</p> <p>b) By 2012</p>
<p>(6.5) Access to good quality local information</p> <p>Disabled young people and their families should receive local and national information at transition.</p>	<p>DfES</p>	<p>DH and DWP</p>	<p>By 2008</p>
<p>(6.6) Disabled young people should be included in planning that is centred on their own needs</p> <p>a) Good practice models for subcontracting most specialist transition support provision should be disseminated.</p> <p>b) DfES and DH should consider mapping youth centred approaches to transition planning, evaluating different models, and informing the development of Individual Learning Plans.</p> <p>c) Promotion of person-centred planning practice nationally.</p>	<p>a) DfES</p> <p>b) DfES and DH</p>		<p>a) 2006 onwards</p> <p>b) 2007 onwards</p> <p>c) By 2010</p>
<p>(6.7) Ensuring advice and guidance is tailored to meet the needs of disabled young people</p> <p>DfES should ensure that arrangements for providing advice and guidance to young people, including Connexions, meet the needs of all disabled young people.</p>	<p>DfES</p>		<p>From 2005</p>
<p>(6.8) Individualised learning and vocational pathways into employment</p> <p>a) New arrangements from Tomlinson group's recommendations to include disabled young people.</p>	<p>a) DfES and LSC</p>		<p>a) 2006 onwards</p>

Summary of recommendations	Lead responsibility	In support	By when
b) Good practice examples should be issued to employers and ACAS on Health and Safety and child protection.	b) DfES		b) 2006 onwards
c) Lifelong Learning UK should develop career structures and skills of staff working with young people with SEN.	c) DfES and LSC		c) 2006 onwards
(6.9) Access to leisure and independent living needs to be ensured a) Code of practice on public sector duty to include increasing opportunities for participation of disabled young people. b) Research on meaningful life options for young people with highest level of needs.	a) DWP b) DH		a) 2005 onwards b) 2005 onwards
Chapter 7: Employment			
(7.1) Rehabilitation a) A set of arrangements for vocational rehabilitation available and accessible for both employers, employees and benefit claimants. b) Joint working between DH and DWP through the Health Safety and Productivity Workforce c) Invite the Academy of Royal Medical Colleges to examine how to increase attention to work as a positive driver for good health.	a) DWP and DH b) DH and DWP b) DH		a) By 2008
(7.2) Occupational health a) Encourage increases in the quality and quantity of OH provision. b) Encourage employers to provide OH services to their employers.	a) DH and DWP b) DH, DWP and HMT		a) 2008 onwards b) 2008 onwards
(7.3) The role of GPs Identify, and assist GPs to adopt, best practice in patient care.	DWP and DH		By 2007
(7.4) Benefits assessments a) Review the processes of assessing eligibility for disability-related benefits.	a) DWP		a) By 2008

Summary of recommendations	Lead responsibility	In support	By when
b) Identify whether the PCA is nearest the optimum point or can be further repositioned.	a) DWP		a) By 2006
(7.5) Capability Report Roll out the Capability Report nationwide, subject to evidence, and over time widen its scope.	DWP		2005 onwards
(7.6) Mainstreaming in the LSC The LSC should aim to increase the proportion of disabled learners in education and training.	DfES	LSC	2006 onwards
(7.7) "Welfare to Workforce Development" Recommendations from this report should be implemented as a matter of priority.	DWP		2005 onwards
(7.8) Employer Training Pilots (ETPs) a) Ensure New Deal for Skills and ETPs meet the needs of disabled people. b) Develop evidence to explain why disabled people appear to fare less well in ETPs and work with LSC on impact measures for disabled people in Apprenticeships.	a) DWP and DfES b) DfES		a) 2005 onwards b) 2005 onwards
(7.9) Connexions and IAG Should have the ability to provide specialist advice to disabled people.	DfES		2005 onwards
(7.10) In-work support through AtW A new system of in-work support through AtW which aims to increase recruitment and retention rates of disabled people.	DWP		By 2010
(7.11) Linking rules and incentives to work a) Provide better guidance to benefit claimants on the linking rules and financial incentives to return to work. b) Deliver changes to the current permitted work rules system, and further investigate the 5-16 hour issue.	a) DWP b) DWP		a) 2006 onwards b) In 2006

Summary of recommendations	Lead responsibility	In support	By when
(7.12) Job broker activity Improve referral arrangements to NDDP Job brokers and develop the role of Job brokers.	DWP		By 2006
(7.13) Supported Employment Increase the flexibility of budgets within the current supported employment programmes.	DWP		2006 onwards
(7.14) Employer awareness Employers should lead a campaign promoting the business benefits of employing disabled people.	DWP and DTI		2006 onwards
(7.15) Advice for employers A single, well known, point of information and advice for employers to be considered.	DWP, DH and DTI		By 2006
(7.16) Jobcentre Plus and employers Develop 'reference sales' products on disability issues for SMEs.	DWP		By 2008
(7.17) Investors in People and the disability symbol a) Review the effectiveness of the disability symbol. b) Consider including employment of disabled people in accreditation criteria and monitor through three year review process. c) Consider consulting with business and trade unions on potential employment standard.	a) DWP b) DfES c) DTI	b) liP	a) By 2007 b-c) Between 2005 and 2007
(7.18) Impact of the public sector duty Public Authorities should take the lead in demonstrating, promoting and reporting on best practice on the recruitment and retention of disabled people.	Government departments, government agencies, local authorities		2006 onwards

Summary of recommendations	Lead responsibility	In support	By when
(7.19) Online directory of services National online directory of service providers should be developed to inform disabled people of the services offered to them and a national helpline.	DWP	DfES and DH	By 2008
(7.20) Employment advice Explore and test options for placing vocational advisors in healthcare and other settings.	DWP and DH		Testing from 2006. Rollout from 2008
Chapter 8: Towards Improved Delivery ³²⁷			
(8.1) An evolving strategy The strategy for improving the life chances of disabled people should be fully developed and timetabled with milestones, communicated widely, and aimed at steady progressive reform to 2025.	Government departments	ODI	Initial activity by 2006, then ongoing
(8.2) A review of provision Provision for disabled people should be reviewed and a new mix of mainstream, specialist and integrated provision derived from the strategy.	Government departments	ODI	Initial activity by 2006, then ongoing
(8.3) Standards More coherent and explicit standards should be developed bringing legislation and other rights into a coherent framework.	Government departments	ODI	Initial activity by 2006, then ongoing
(8.4) Incentives for effective delivery A review of provision should address ways of incentivising effective delivery of services which meet the needs of disabled people.	Government departments	ODI	Initial activity by 2006, then ongoing

³²⁷ Chapter 8 recommendations will require the ODI to fulfil its specific responsibilities, which will require the active involvement of other Government Departments, as well as other Government Departments fulfilling the responsibilities they have outside of the ODI remit.

Summary of recommendations	Lead responsibility	In support	By when
(8.5) Government leadership of reform A strong focus is required within Government to ensure that priority is given to disability issues, and to provide oversight of a process to reform delivery in line with the public service reform agenda.	Government departments	ODI	Initial activity by 2006, then ongoing
(8.6) Participation New arrangements should be established for securing participation of disabled people in policy design and delivery at all levels.	Government departments	ODI	Initial activity by 2006, then ongoing
Chapter 9: Implementation			
(9.1) Developing measurables Develop specific, outcome-based indicators to enable progress on the recommendations in this report to be measured.	ODI	Government departments	From 2005

Annex A: The role of the Strategy Unit

The Strategy Unit was created by a merger of the Performance and Innovation Unit, the Prime Minister's Forward Strategy Unit and part of the Policy Studies Directorate of the Centre for Management and Policy Studies. The unit performs a range of functions, including long-term strategic reviews of major areas of policy, studies of cross-cutting policy issues, strategic audits and joint work with departments to promote strategic thinking and improve policy-making across Whitehall.

The Strategy Unit reports to the Prime Minister through the Chancellor of the Duchy of Lancaster and the Cabinet Secretary.

Comprehensive information about the work of the Strategy Unit and its projects can be found on the Strategy Unit's web-site at www.strategy.gov.uk.



Annex B: Project team, Sponsor Minister, Advisory Group and Expert Groups

This report was prepared by a multi-disciplinary team guided by a Sponsor Minister, an Advisory Group and three Expert Groups.

The Strategy Unit project team is described in Section B.1 of this annex. The Sponsor Minister is named in Section B.2. Section B.3 describes the composition of the Advisory Group and the three Expert Groups.

B.1 The Strategy Unit project team

The Strategy Unit team included team members with experience in economics, policy-making and issues affecting disabled people. The team was made up of a mix of some civil servants and some drawn from outside Whitehall.

The project team comprised:

Stephen Aldridge
Chief Economist and Deputy Director, Strategy Unit

Esmee Brenells
Strategy Unit

Ian Coates (team leader)
Strategy Unit

John Fuller
Department for Work and Pensions, on secondment to the Strategy Unit

Nicholas Garland
Strategy Unit

Sarah James
Essex County Council, on secondment to the Strategy Unit

Tina Karageorghis
Strategy Unit

Halima Khan
Strategy Unit

Dr Rannia Leontaridi
Economist, Strategy Unit

Clare Lombardelli
Economist, Strategy Unit

Sally McManus
National Centre for Social Research, on secondment to the Strategy Unit

Suzanne Moroney
National Employment Panel, Department for Work and Pensions, on secondment to the Strategy Unit

Dr Jenny Morris
Consultant

Additional assistance was provided by **Sharon Clowery** from the Department for Work and Pensions.

Research assistance was provided by **Laura Gregory** (Strategy Unit) and by **Lucy McKee** (on work placement from the Government and Opposition Whips Office, Cabinet Office).

B.2 The Sponsor Minister

The work of all Strategy Unit teams is overseen by a Sponsor Minister, in this case **Maria Eagle**, Minister for Disabled People in the Department of Work and Pensions.

B.3 The Advisory Group and Expert Groups

The project team appointed an Advisory Group and three Expert Groups to assist with the analysis. Individuals were selected to give a range and balance of expertise and backgrounds. The Advisory Group met on four occasions to consider the Strategy Unit's:

- initial assessment of priority areas and common themes;
- analysis of the issues;
- vision for the future; and
- draft final report.

The three Expert Groups discussed separate strands of the overall analysis – early years, the employment perspective and independent living. All groups played a crucial part in the project, but were advisory, and this report does not necessarily reflect

their views. The Strategy Unit is indebted to all those who gave of their time to participate on the advisory or expert groups.

Advisory Group Members

Stephen Aldridge

Chief Economist and Deputy Director, Strategy Unit

Baroness Cathy Ashton

(**Phil Snell** attended three meetings on Baroness Ashton's behalf) Parliamentary Under Secretary of State, Department for Education and Skills/Department for Work and Pensions

Jane Campbell MBE

Chair, Social Care Institute for Excellence

Maria Eagle MP

Minister for Disabled People, Department for Work and Pensions

Bruce Calderwood

Department for Work and Pensions

Yvette Cooper MP

(**Sheila Fletcher** attended twice on Yvette Cooper's behalf) Parliamentary Under Secretary of State, Office of the Deputy Prime Minister

Gareth Davies

No. 10

Ann Frye

Department for Transport

Nicholas Holgate

HM Treasury

Dr Stephen Ladyman MP

(Ian Berry attended once on Dr Stephen Ladyman's behalf)
Parliamentary Under Secretary of State for Community, Department of Health

Christine Lenehan

Director, Council for Disabled Children

Bert Massie CBE

Chair, Disability Rights Commission

Norman Glass CBE

Chief Executive, The National Centre for Social Research

Mark Thompson

Director-General, BBC

Claire Tyler

(Ruth Stanier attended two meetings on Claire Tyler's behalf)
Social Exclusion Unit, Office of the Deputy Prime Minister

Sally Witcher

Chair, Disability Employment Advisory Committee

Early Years Expert Group**Francine Bates**

Chief Executive, Contact A Family

Lesley Campbell

Children's Officer, Mencap

Gill Edelman

Chief Executive, I CAN

Christine Lenehan

Director, Council for Disabled Children

Nigel Nicholls

Trustee, Contact A Family

Dr Philippa Russell CBE

Disability Rights Commissioner, National Children's Bureau

National Employment Panel Employers' Expert Group**Sly Bailey**

Chief Executive, Trinity Mirror

Catherine Brown

Managing Director, BUPA Wellness
Lawrence Churchill Chair Designate, Pension Protection Fund

Neil Couling

Director, South East Region
Jobcentre Plus

Adam Crozier

Chief Executive, Royal Mail Group plc

Philip Friend

Partner and Director, Churchill & Friend

Lorraine Gradwell

Chief Executive, Breakthrough UK

Steve Harvey

Director of People & Culture, Microsoft Ltd

Marilyn Howard

Consultant

Maurice Ostro

Managing Director, Air Fayre Limited

Michael Richardson

Director, Welfare, Work and Poverty Directorate, Department for Work and Pensions

Rob Sykes

Chief Executive,
Worcestershire County Council

Bob Warner

Chief Executive, Remploy Limited

Independent Living Expert Group

Dr Ian Basnett

Consultant in Public Health

Nasa Begum

Principal Adviser Participation, Social
Care Institute for Excellence

Peter Beresford

Professor of Social Policy, Brunel
University, Chair of Shaping Our
Lives and long term user of mental
health services

Peter Campbell

Mental health system survivor

Nick Danagher

Chief Executive of Surrey
Independent Living Council

John Evans

President of the European network
of Independent Living, founder
of the Hampshire Centre for
Independent Living

Frances Hasler

Chief Executive, National Centre
for Independent Living

Ann Macfarlane MBE,
Rights and Independent
Living consultant

David Morris

Senior Policy and Project Manager,
Greater London Authority

Abina Parshad Griffin

Mental Health Action Group,
Disability Rights Commission

Rachel Perkins

Clinical Director and Consultant
Clinical Psychologist, Adult Mental
Health Services, South West London
& St. George's Mental Health NHS
Trust, Vice Chair of the Manic
Depression Fellowship, Mental
Health Service User

David Pugh

Chair, Manic Depression Fellowship

Liz Sayce

Director,
Policy and Communications,
Disability Rights Commission

Annex C: Bilateral discussions and an overview of the consultation processes

The Strategy Unit drew on a wide range of expertise and experience in formulating this report.

Section C.1 of this annex lists the organisations and individuals that engaged with the Strategy Unit team in face-to-face bilateral discussions and site visits.

Sections C.2 to C.4 provide an overview of the range of other consultation processes undertaken. Section C.2 outlines the shadowing of disabled people that team members undertook.

The programme of focus group consultations with disabled people (of varying ages and impairments), their families, and service providers is introduced in Section C.3, and detailed more fully in Annex D. Section C.4 introduces the written correspondence with stakeholders and experts that also provided important input to the project, these are summarised in Annex E.

C.1 Bilateral discussions

The team was assisted by being able to draw on the experience and advice of a number of experts and stakeholders who attended face-to-face bilateral discussions with and/or organised site visits for the team.

We would like to thank the following for their input:

Action for Blind People
 Advisory, Conciliation and Arbitration Service (ACAS)
 Association of Directors of Social Services (ADSS)
 Aiding Communication in Education (ACE)
 Air Fayre Ltd
 aMaze
 Aylesbury Community Head Injury Service
 Barnado's
 Baskerville School, Birmingham
 BBC, Mark Thompson
 BBC Strategy Unit
 Beaumont College, Lancaster
 Blue Arrow
 Breakthrough UK Ltd
 Bristol Disabled Living Centre
 British Council of Disabled People (BCODP)
 British Deaf Association (BDA)
 British Medical Association (BMA)
 British Society for Rehabilitational Medicine, Andrew Frank
 Brunel University, Deborah Mabbett
 BskyB

BUPA
 Cabinet Office
 Centre for Analysis of Social Exclusion (CASE), London School of Economics and Political Science (LSE)
 Centre for Research in Social Policy (CRSP), Loughborough University
 Chelwood Nursery School
 The Cherry Trees School
 Churchill and Friend
 Civil Service Disability Working Group
 Council for Disabled Children (CDC)
 Commission for Social Care Inspection (CSCI)
 Confederation of British Industry (CBI)
 Connexions Cornwall-Devon
 Connexions Nottinghamshire
 Contact a Family
 Cornell University, Susanne Bruyere
 Lesley Dee, Cambridge University
 Disability Employment Advisory Committee (DEAC)
 Demos
 Department for Culture, Media and Sport (DCMS)
 Department for Education and Skills (DfES)
 Department for Work and Pensions (DWP)
 Department for Transport (DfT)
 Department of Health (DH)
 Department of Employment and Learning (DEL), Northern Ireland
 Department for Environment, Food and Rural Affairs (Defra)
 Department of Trade and Industry (DTI)
 Direct Payments Service, Bristol
 Disability Alliance
 Disability Awareness in Action (DAA)
 Disability Matters Disability Rights Commission (DRC)
 Disabilities Trust
 Disabled People South Africa
 Early Support Programme DfES/RNID
 Equalities
 Employers Forum on Disability
 Essex Coalition of Disabled People
 Essex County Council
 Essex Independent Living Advocacy
 Federation of Small Businesses
 Julie Fernandez, actress and campaigner
 Foundation for People with Learning Difficulties
 Hammersmith and Fulham Council
 Headway
 Health Development Agency, Mike Kelly
 HM Treasury
 Home Office
 Marilyn Howard, independent consultant
 ICAN
 Independent Living Advocacy Limited

Institute of Fiscal Studies (IFS),
James Banks
Jobcentre Plus
Joseph Rowntree Foundation (JRF)
Kent County Council
Kings Fund
Learning and Skills Council (LSC)
Learning Disability Task Force
Leonard Cheshire Foundation
London Borough of Hammersmith
and Fulham, Ravi Gurumurthy
Low Incomes Tax Reform Group
Mencap
Microsoft
MIND (National Association for
Mental Health)
MS Society
National Autistic Society (NAS)
National Centre for Independent
Living (NCIL)
National Centre for Social Research
(NatCen)
National Children's Bureau (NCB)
National Forum of People with
Learning Difficulties
National Health Innovations
Network, Bob Grove
National Library for the Blind
National Service Framework for
Long Term Conditions
National Union of Students (NUS)
National Youth Agency
New Zealand Disabled People's
Association
New Zealand Office of Disability
Issues
Norah Fry Centre, Bristol
Nottingham University, Sonali Shah
and Jill Pascall
Nottinghamshire County Council
Number 10 Downing Street
Office of the Deputy Prime Minister
(ODPM)
Options for Independent Living
Housing and Transport Groups Essex
Geraldine Peacock – Civil Service
Commissioner
People First
RADAR
Remploy
Royal Mail Group plc.
Royal National Institute of the Blind
(RNIB)
Royal National Institute of the Deaf
(RNID)
St Michael's RC Secondary School
SCOPE
Scottish Executive
SCOVO
Shaw Trust
SKILL
Small Business Service (SBS)
Social Care Institute for Excellence
(SCIE)
Social Exclusion Unit (SEU), ODPM
Social Market Foundation
Social Policy Research Unit (SPRU),
York University
South Africa Office on the Status of
Disabled People
Suffolk County Council, including
young people consultation group

Sure Start Unit , Tania Burchardt
 Trades Union Congress (TUC)
 Triangle
 Trinity Mirror
 Turning Point
 University of Bristol, Paul Gregg
 University of Cambridge, Holly Sutherland
 University of Leeds, Colin Barnes
 University of Leeds, Gerald Wistow
 UnumProvident
 Values into Action
 Valuing People Support Team
 Welsh Assembly Government
 Welsh Centre for Learning Difficulties
 West England Centre for Inclusive Living (WECIL)
 Worcester County Council
 WorkWAYS, Exeter
 Young Minds
 Zurich Financial Services

C.2 Shadowing

Members of the project team shadowed disabled people in a variety of settings in order to learn from their personal perspective. The Strategy Unit is most indebted to these individuals and extends to them its particular thanks.

C.3 Focus group consultations

The Strategy Unit team benefited from a programme of 'focus group'

consultations with disabled people (of varying ages and impairments), their families, and service providers. These are described more fully in Annex D, which is published separately from the main report at www.strategy.gov.uk

C.4 Written submissions received

Written correspondence with stakeholders and experts also provided key input to the project, and these are summarised in Annex E, which is published separately from the main report. Submissions were invited via the Strategy Unit website in response to publication of the project's Interim Report. The full papers and responses to them are available at www.strategy.gov.uk