



Office for Disability Issues

HM Government



Independent Living

A cross-government strategy about independent living for disabled people

DWP Department for Work and Pensions

department for children, schools and families

Department for **Transport**

Communities and Local Government

(DH) Department of Health

Department for **Innovation, Universities & Skills**

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Foreword by the Prime Minister



Our vision for Britain is of a society where all citizens are respected and included as equal members, and where everyone has the opportunity to fulfil their potential. For many disabled people that vision can seem far removed from the reality of their lives. But the lives of some have been transformed by having choice and control over the support they need. We are committed to extending such self-determination to all disabled people, and to enabling greater access to housing, employment, health, education, transport and other opportunities.

Involving disabled people of all ages in how services are planned and delivered means individuals are supported in the ways that they choose and barriers to access removed. Transferring power to those needing support, and joining up services to ensure this happens, changes the way in which support and services are delivered and experienced. It unlocks opportunities, enables people to participate and contribute, and strengthens our communities.

The Independent Living Strategy has been developed with disabled people. I am grateful to Baroness Jane Campbell, who chaired the Expert Panel supporting the Review, and to all the Panel members who provided challenging and constructive advice. The involvement of disabled people in workshops and regional discussions has been essential in shaping this Strategy and I am grateful to all those who took part.

A guiding principle of the Review has been to work across Government to improve the outcomes for disabled people by breaking down the artificial barriers created by fragmented initiatives and organisational boundaries. I am delighted that Ministers in Communities and Local Government, Transport, Children, Schools and Families, Innovation, Universities and Skills, Work and Pensions, and Health have come together to champion independent living and to develop and agree joint ownership of this Strategy.

We are committed to a vision of equality for all disabled people by 2025. This Strategy sets out how we will make progress towards achieving that goal.

A handwritten signature in black ink that reads "Gordon Brown".

Gordon Brown

Foreword by Life Chances Ministers

The Strategy brings together a number of initiatives – across Government – which will enable more people to have choice and control over the support they receive, remove barriers to independent living, and improve access to services. For example, a Transition Support Programme will enable young disabled people to access advocacy support and person centred planning; a cross-government national strategy will aim to help people remain in employment when they acquire an impairment or their condition worsens; and a nationally funded rapid response repairs and adaptations services will enable older and disabled people to remain living in their own homes. The Strategy includes measures to encourage the investment of resources to enable disabled people to have control over the resources made available to them. We will also examine the need for advocacy support in situations where people are at risk of losing choice and control.

We want to ensure that independent living – having choice and control over support – is a goal for disabled people of all ages and across all service user groups. For example, older disabled people must have the same options and opportunities for independent living as anyone else and the Strategy contains a number of commitments which will help achieve this goal.

Disabled people have told us that one of the barriers to change is lack of understanding about what independent living means. An important part of the Strategy will be action to promote understanding among service deliverers of how to enable people to have choice and control so that independent living and a personalised approach are integral to the way services are planned and delivered.

A key element of the Strategy is our framework for measuring progress. Together with disabled people, we will monitor progress on the Strategy annually to ensure it does make a tangible difference to people's lives. Where progress is slow we will consider what further action is required.

Foreword by Life Chances Ministers

This Strategy sets out our commitments to work together to deliver real improvements in the lives of disabled people.



A handwritten signature in black ink that reads "Anne McGuire".

Anne McGuire MP
Minister for Disabled
People



A handwritten signature in black ink that reads "Bill Rammell".

Bill Rammell MP
Minister of State for Life
Long Learning, Further
and Higher Education



A handwritten signature in black ink that reads "Rosie Winterton".

**Right Honorable
Rosie Winterton MP**
Minister of State for
Transport and Minister
for Yorkshire and
Humber



A handwritten signature in black ink that reads "Andrew Adonis".

Lord Andrew Adonis
Parliamentary Under
Secretary of State for
Schools and Learners



A handwritten signature in black ink that reads "Kay Andrews".

**Baroness Kay Andrews
OBE**
Parliamentary Under
Secretary of State for
Communities and Local
Government



A handwritten signature in black ink that reads "Ivan Lewis".

Ivan Lewis MP
Parliamentary
Under Secretary
of State for Care
Services (Minister
for Care Services)



Executive summary

Executive summary

- We want to create a society where everybody is treated with dignity and respect and has the chance to fulfil their potential and unlock their talent. We need to ensure that disabled people are a full part of this agenda.
- The Government is therefore committed to delivering on full and equal citizenship for disabled people and sees independent living as being part of the way we advance this. Independent living enables disabled people to fulfil the roles and responsibilities of citizenship.
- This Independent Living Strategy sets out a strategy to improve disabled people's experiences and life chances. It is a cross-government strategy because it is only through all Departments working together can we really deliver for disabled people.
- It is the Government's ambition that by 2013 disabled people have more choice and control over how their needs for support and/or equipment are met. We also need to make significant progress in tackling barriers to disabled people's access to health, housing, transport, and employment opportunities.
- The personalisation of services is one element of the wider cross-government Strategy on independent living. Giving disabled people greater choice and control over the support they need and the resources available to them is important, not just in social care, but across mainstream services as well – housing, transport, health, employment, education and training – and across all age groups, including young disabled people in transition to adulthood and older disabled people.
- We acknowledge that there is a gap between national policy and people's real experiences. This Strategy will begin to fill this gap.
- The Strategy has been developed in partnership with disabled people to ensure that it reflects their knowledge and real life experiences of the barriers to independent living.

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- The Strategy includes new investment from Government, and is also about using current resources in more effective and empowering ways.
- This is a five year Strategy and we will look every year at what progress we are making. We believe that this change can be achieved without new legislation but, we are committed to reviewing the situation if delivery does not happen.

Background

1. In 2006 an Independent Living Review was set up to make progress on the Government's commitment that all disabled people, (including older disabled people), have the same choice, freedom, dignity and control over their lives as non-disabled people. The Review followed the commitment made by the Government in 2005 to deliver independent living for all disabled people.¹
2. The Review was given the task of developing a cross-government five year Strategy to deliver independent living. The Independent Living Strategy sets out the Government's policy commitments, identifying what difference these policies are intended to make, and how this will be measured and monitored.
3. In addition, the Strategy makes proposals for the involvement of disabled people, (including older disabled people), and their organisations in the implementation of the Strategy and invites responses to these proposals.
4. A case study approach was taken to developing evidence-based policies. The Strategy covers transition to adulthood (from the age of 14) through to very old age. Disabled people were involved throughout the course of the Review.

1 Prime Minister's Strategy Unit, Cabinet Office, (2005), 'Improving the Life Chances of Disabled People'

What does independent living mean?

5. Disabled people, (including older disabled people), have challenged the meaning of 'independence'. 'Independent living' does not mean doing things for yourself, or living on your own. Instead, it means:
 - having choice and control over the assistance and/or equipment needed to go about your daily life
 - having equal access to housing, transport and mobility, health, employment and education and training opportunities.
6. Everyone needs assistance or equipment of some kind. However, many people with physical and/or sensory impairments, learning disabilities, mental health support needs, long-term health conditions or who experience frailty associated with old age, have additional needs for assistance. Some of these additional needs are the result of disabling barriers, such as the need for a taxi if public transport is inaccessible. Others are integral to having a particular impairment or condition, such as the need for a lightwriter for someone who does not use speech, or assistance with daily living for someone who has dementia.
7. Too often these additional needs for assistance or equipment have been met in ways which do not give people choice and control. Instead, others decide on behalf of disabled people how assistance should be provided and this can lead to segregation and social exclusion. This is particularly so for older people and for people with significant levels of cognitive and/or communication impairments.
8. It is important to recognise that anyone, whatever their level of impairment, can express preferences and therefore express choices about how their needs should be met. Our aim is to ensure that all disabled people, including those with significant learning disabilities or other forms of cognitive impairment (including dementia), are enabled to have choice and control over how their support needs are met.

Executive summary

9. Unpaid carers, that is family members and friends, play a key role in the lives of many disabled people and often the care that they provide is a key factor in helping disabled people to remain in their own homes and participate in society. The Government is currently reviewing its National Carers Strategy to evaluate where it can better support carers to enable them to also have choice and control in their lives in this important role.

Vision and aims of the Strategy

10. The Government wants every locality to have a single community based support system which focuses on all aspects of what people need to maximise their health and wellbeing and to participate in family and community life. The right of the individual disabled person to determine the kinds of services and support that they need will be at the heart of this reformed system.
11. Such choice and control will help disabled people overcome the barriers that they face in participating in, and contributing to, society. The Government is therefore committed to enabling disabled people to have choice and control over the support they need to live their everyday lives. The fulfilment of this commitment will be a vital part of delivering the 2025 vision of full and equal citizenship set out in 'Improving the Life Chances of Disabled People'.²
12. The aim of the five year Independent Living Strategy is that:
 - disabled people who need support to go about their daily lives will have greater choice and control over how support is provided
 - disabled people will have greater access to housing, transport, health, employment, education and leisure opportunities and to participation in family and community life.
13. Progress towards this vision and aim will be measured and reported on annually to the Life Chances Ministerial Group. If satisfactory progress is not made on delivering independent living, the Government will review the need for new legislation.

2 Prime Minister's Strategy Unit, Cabinet Office, (2005), 'Improving the Life Chances of Disabled People'.

The Independent Living Strategy

14. The Independent Living Strategy includes the following Government commitments:

1. **Promoting independent living:** To promote a shared understanding of the principles and practice of independent living we will:
 - develop a programme to build awareness and change attitudes in order to create support for an independent living approach
 - develop communication materials for practitioners to effectively explain the case and the ways of promoting it
 - use these materials to communicate independent living messages to a wide range of practitioners
 - communicate this agenda to disabled people with a particular focus on ‘seldom heard’ groups, for example, black and minority ethnic (BME) disabled people, older disabled people with high support needs, and young people with autistic spectrum disorder.
2. **Action and Learning Sites and Regional Initiatives:** We will strengthen the evidence-basis to inform future policy development and investment, and demonstrate how to use resources to better promote choice and control. We will develop two initiatives:
 - action and learning sites to demonstrate the redeployment of resources from professional assessment and care management to user-led support, advocacy and brokerage
 - a regional initiative to demonstrate how we can invest in independent living for older disabled people in residential/nursing care or at risk of moving into care.
3. **Housing:** We will take action to maximise disabled people’s housing opportunities and choices by:
 - increasing the provision of housing advice and information
 - updating the Lifetime Homes standard, making it an essential element in the Code for Sustainable Homes and making adherence to it mandatory for all public sector funded housing by 2011

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- setting a clear target for the construction of all new housing to Lifetime Homes standard by 2013, with a commitment to review progress against this target by 2010
 - encouraging the adoption of Accessible Housing Registers and supporting the dissemination of good practice models
 - investing in rapid response repairs and adaptations services
 - developing a method to enable early identification of individuals who are at risk of health and care crises
 - increasing funding for, and improving, the Disabled Facilities Grants (DFG) system
 - continuing to invest in the Supporting People programme which promotes independent living by providing housing related support.
4. **Transport and mobility:** We will consolidate progress made in the areas of training, information, and accessibility in public transport and consider action required to enhance the mobility opportunities of people whose needs cannot be met by public transport. We will do this by:
- enhancing personal mobility and transport choices for disabled people based on evidence of what works
 - promoting the training of transport providers in the needs of disabled people
 - developing a strategy to provide information and confidence training for disabled people in using transport
 - working with local authorities to ensure accessibility planning is reflected in Local Transport Plans and Local Area Agreements
 - improving disabled people's participation in the development and implementation of transport policies.

5. **Health:** Our Strategy aims to enhance the understanding of health services' contribution to independent living, to enable disabled people to have choice and control over their non-acute healthcare needs, and to enable them to manage their own long-term conditions. We will do this by:
 - designing and delivering an education and awareness programme for National Health Service (NHS) staff on increasing choice and control, and on the Disability Equality Duty (DED)
 - increasing the take-up of self-management programmes, such as the Expert Patients Programmes, and develop new approaches that work for disabled people
 - scoping good practice in enabling people to have choice and control over their continuing health care needs, and publishing good practice guidance.

6. **Employment and economic wellbeing:** We want to enable individuals to remain in employment when they acquire an impairment or when an existing impairment or condition deteriorates. We will also ensure that benefit and charging systems, and recent reforms, do not create unnecessary barriers to independent living. We will:
 - act to improve specialist employment support services for disabled people
 - develop a cross-government national strategy to enable people to remain in employment when they acquire an impairment or their condition worsens
 - increase access to volunteering opportunities for disabled people
 - change benefit reclaim processes and, if required, regulations to address disincentives and enable participation in public and civic life
 - examine the combined impact of reforms to the benefit system (Employment Support Allowance (ESA), Housing Benefit), employment support programmes, and charging policies within adult social care, to assess their role in promoting disability equality

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- consult on amending guidance on charging for residential care, (in line with current guidance on charging for community services), to remove the current disincentive to paid employment. The Department of Health (DH) will be considering this proposal, along with other proposals to amend the Charging for Residential Accommodation Guide (CRAG)
- review how Disability Living Allowance (DLA) and Attendance Allowance (AA) can better support independent living.

7. **Personalisation, choice and control:** We will support the transformation of social care to deliver a system which will focus on timely, preventative and high quality personally tailored services. We want everyone – whether they receive state-funded support or fund support themselves – to have maximum control and power over the support services they receive and we will work with local authorities and key partners to help them deliver this. The long-term aim will be to ensure that every disabled person in receipt of social care, and/or related funding, has the opportunity to have choice and control over the state funding they receive. We will promote:

- increased personalisation of support through, for example, individual budgets and direct payments
- a strategic shift towards investment in early intervention and preventative approaches through initiatives such as the Partnerships for Older People Projects (POPP)
- the development of user-led organisations
- access to better information, advocacy and support so that people are able to navigate health and social care systems
- the take-up of direct payments.

8. **Support, information, advocacy and brokerage:** Effective support, information, advocacy and brokerage services are a key aspect of enabling disabled people to make choices for themselves that might otherwise be made for them by other people. Our policy of transforming social care includes a commitment to a universal information, advice and advocacy service for people who need support in their lives. In particular:
- local organisations should consider the needs of disabled people within their community for support, information, advocacy and brokerage services and should consider co-ordinating their approaches through local strategic partnerships (LSPs)
 - we will examine the case for investment in advocacy support in situations where disabled people are particularly at risk of losing choice and control
 - the Department of Health (DH) will invest in Action and Learning Sites to deliver the Life Chances commitment that by 2010, each locality will have a user-led organisation modelled on existing Centres for Independent Living (CILs)
 - the Department of Health (DH) will develop a National Advocacy Qualification for independent advocates.
9. **Older people:** We will promote a co-ordinated, strategic approach to investing in independent living for older disabled people, and will also seek to ensure that older disabled people's voices are heard and that they are enabled to participate in the development and delivery of services. Most of the commitments in this Strategy will promote independent living for older disabled people.

In addition:

- the Office for Disability Issues (ODI), in partnership with other government departments, will develop and publish a cross-government toolkit that provides a 'one stop' information resource on independent living for older people at a national, regional and local level

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- the Office for Disability Issues (ODI) will investigate the case for investing in independent living for older disabled people in residential/nursing care or at risk of moving into care.

10. **Young disabled people in transition to adulthood:** We will seek to ensure a seamless transition into adulthood for young disabled people, including those with complex health needs, in all aspects of their life, including between children's and adults' services, as well as housing, transport, employment, education and training. We will:

- as a first step, deliver a Transition Support Programme for 14-19 year olds, which will promote joint working, a holistic approach, and include access to an advisor or key worker, advocacy and support, and person centred planning approaches
- in the longer-term, learn from, and build on, this Programme to improve practice in supporting the transition from childhood to adulthood between the ages of 14-25
- deliver the cross-government strategy for post-16 learners with learning difficulties/disabilities which aims to create more sustainable and seamless services
- carry out a public consultation on specialist disability employment programmes for disabled people who face complex barriers to enter and retain employment
- reduce the proportion of young people aged between 16 and 18 who are not in education, employment or training
- support young disabled people to become independent users of transport
- address the housing needs of young disabled people by their inclusion in action to prevent homelessness amongst young people, paying particular attention to those with mental health support needs
- support young disabled people to become active members of their community through their inclusion in the Young Advisors Programme
- carry out a scoping study with a view to piloting and evaluating individual budgets for disabled children and young people.

11. **Disabled parents:** We will promote more joined-up working between health, education and social care to provide timely and flexible support where this is needed by families affected by parental disability. We will also encourage policies and services aimed at parents in general to include families affected by parental disability. Specifically, we will:
- promote good practice in children's and adults' health, education and social care by encouraging the development of inter-agency protocols to support disabled parents and their children
 - include parents with learning disabilities and parents with mental health support needs in local pathfinders to deliver intensive and tailored family support
 - ensure that all information produced by government departments aimed at parents will be made available in accessible formats
 - assist local authorities to develop a more strategic and joined-up approach to parenting support and to strengthen the use of evidence-based parenting interventions through extended schools' and children's centres
 - work across Government, to ensure those policies which tackle child poverty and unemployment, address the needs and circumstances of families affected by parental disability.
12. **Measuring progress:** We are committed to monitoring progress on the aims of the Strategy and the vision it represents. We shall use the new performance framework, in particular the Equalities Public Services Agreement (PSA) to do this.
- the Office for Disability Issues (ODI) will publish progress on the Independent Living Strategy, as part of the Office for Disability Issues (ODI) annual reporting process
 - Life Chances departments will review in time for the next Spending Review and performance framework whether further action to deliver outcomes is needed
 - the Government will review the need for legislation if sufficient progress has not been made against the outcomes by 2013.




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Consultation on implementation of the Strategy and the involvement of disabled people

15. Disabled people have told us there is too big a gap between national policy aims and local implementation. They also told us that they should be involved in both the development and the implementation of policies which affect their lives and services which aim to meet their needs. We are consulting on how to do this.

Monitoring implementation of the Independent Living Strategy

16. The Office for Disability Issues (ODI) Board of Management and Life Chances Ministerial Group will champion a cross-government approach to independent living and monitor progress annually. The framework for monitoring progress is set out in **Annex C**.
17. In addition, we propose to set up an Independent Living Scrutiny Group to monitor progress annually and report to the Office for Disability Issues (ODI) Board of Management and Ministerial Group. Membership would include members of Equality 2025 and additional members drawn from the Expert Panel which advised the Independent Living Review.

Consultation question 1:

We would welcome views on how best to involve disabled people, at a national level, in the monitoring of progress on implementation of the Independent Living Strategy, for example, by setting up an Independent Living Scrutiny Group.

Promoting the involvement of disabled people

18. The new local government performance framework will encourage the involvement of disabled people in the commissioning and delivery of local services. In addition, the Disability Equality Duty (DED) promotes the ongoing involvement of disabled people. The Department of Health's (DH) work to establish a user-led organisation in every locality by 2010 could provide local focal points for engaging disabled people in the implementation of the Strategy. Other initiatives, such as Local Involvement Networks (LINKs), aim to promote local people's involvement in shaping services.

Consultation question 2:

We would welcome views on current arrangements for promoting the involvement of disabled people and their organisations and the contribution these arrangements may make to the monitoring of the Independent Living Strategy

19. There are many existing networks of disabled people which could be drawn together to provide a resource for the involvement of disabled people at local and regional levels in implementing the Independent Living Strategy.

Consultation question 3:

Is there a need for a “network of networks” to facilitate the involvement of disabled people in the implementation and monitoring of the Strategy?

Developing leadership capacity amongst disabled people

20. The Independent Living Review’s Expert Panel advised us of the importance of building leadership capacity amongst disabled people of all ages. They suggested that Partners in Policymaking™ courses would be useful in promoting disabled people’s involvement in implementing the Strategy.³

Consultation question 4:

We would welcome views on current initiatives to build leadership capacity amongst disabled people, on whether further work should adapt the Partners in Policymaking™ model, and/or whether there are other models we should consider.

3 Partners in Policymaking website: <http://www.partnersinpolicymaking.co.uk/index.php>

Supporting implementation

21. The Expert Panel identified a range of different mechanisms to support delivery of the Strategy. The Government Offices for the Regions play a key role and there is a need to assist them to support local strategic partnerships (LSPs) to deliver independent living policies, linking with user-led organisations, and monitoring implementation. We will be producing targeted information and guidance for Government Offices for the Regions, including toolkits, as set out in the Strategy. We would welcome views on what other action may be required.

Consultation question 5:

We would welcome views on the best ways to assist implementation and monitoring of the Strategy at regional and local levels.

Consultation question 6:

We would welcome any other views on the Independent Living Strategy.

Consultation

The consultation period begins on 3rd March 2008 and runs until 20th June 2008. Please ensure your response reaches us by that date. We will publish the results of the consultation. Please send your consultation responses to:

Independent Living Strategy Consultation

Office for Disability Issues

Department for Work and Pensions

The Adelphi

1-11 John Adam Street

London WC2N 6HT

Telephone: 0207 712 2845

Textphone: 0207 712 2032

Fax: 0207 962 8096

Email: independent-living-review@dwp.gsi.gov.uk

VISION AND OUTCOMES FRAMEWORK FOR INDEPENDENT LIVING STRATEGY

Vision: All disabled people will have the same choice, control and freedom as every other citizen and any support is based on individuals’ own choices and aspirations

Greater choice and control

Greater access to housing, transport, health, employment, education and leisure opportunities

Participation in family and community life

NB: The outcome measures set out below are examples only. Full details of measures are given in Annex C

Choice and control (PSA 15, 19)	Local councils’ performance on the seven health, and social care outcomes (CAA)	Satisfaction of older people with home and neighbourhood (PSA 17)	Gap in employment rates between disabled and non-disabled people (ODI Life Chances Indicator PSA 8)	Employment /independent living and mental health or learning disability (PSA 16)	Perception of dignity and respect when accessing public services (PSA 15)	Participation in cultural, sporting and leisure activities (ODI Life Chances Indicator)	Disabled parents’ access to childcare (ODI Life Chances Indicator)
Provision of advice, assistance and support (PSA 19)	Numbers accessing self-directed support (DH DSO)	Disabled people in poor housing conditions or housing not suited to their needs (ODI Life Chances Indicator)	Disabled individuals living in income poverty (ODI Life Chances Indicator)	Experience of using public transport (ODI Life Chances Indicator)	People supported to be in control of their condition (DH DSO)	Participation in public life (PSA 15)	Outcomes for those in receipt of housing support (Supporting People outcomes framework)
Independent living (PSA 17, 18)						Volunteering levels (ODI Life Chances Indicator)	

PSA = Public Service Agreement

CAA = Comprehensive Area Assessment

DSO = Departmental Strategic Objectives



1. Visions, aims and outcomes

Chapter 1 – Visions, aims and outcomes

Introduction

1. The Independent Living Review was set up in July 2006 to make progress on the Government's aim that all disabled people, (including older disabled people), should be able to live autonomous lives, and have the same choice, freedom, dignity and control over their lives as non-disabled people. The Review followed the commitment made by the Government in 2005 to deliver independent living for all disabled people.¹
2. The Review was given the task of developing a five year Strategy to deliver independent living. This report sets out the Government's policy commitments which make up this five year Strategy (Chapter 2), identifying what difference these policies are intended to make, and how this will be measured (Chapter 3 and **Annex C**).
3. In addition, the report makes proposals for the involvement of disabled people (including older disabled people) and their organisations in the implementation of the Strategy and invites responses to these proposals (Chapter 4).

Our approach to developing the Strategy

4. The Review has taken a case study approach to developing evidence-based policies so that the Strategy is grounded in the lived experiences of disabled people. It has not covered young children but has encompassed transition to adulthood (from the age of 14) through to very old age. The Strategy seeks to address not only the barriers experienced by all disabled people but also those faced by particular groups, such as disabled people from black and minority ethnic (BME) communities, older people with high support needs, young people with autistic spectrum disorder, (to name only three groups amongst many).

1 Prime Minister's Strategy Unit, Cabinet Office, (2005), 'Improving the Life Chances of Disabled People'.

Chapter 1 – Visions, aims and outcomes

5. We have involved disabled people throughout the course of the Review, and details of their involvement, including information about our Expert Panel, are set out in **Annex A**.

Disabled people, (including older disabled people), have challenged the meaning of ‘independence’.

Independent living does not mean:

- doing things for yourself
- living on your own.

Independent living does mean:

- having choice and control over the assistance and/or equipment needed to go about your daily life
- having equal access to housing, transport and mobility, health, employment, education and training opportunities.



What does independent living mean?

6. The Government has adopted disabled people's own definition and vision of independent living, independent living means:

'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 aspirations.'²

What does independent living mean to disabled people?

- Choice and control
- Being included
- Participating
- Having equal access
- Freedom
- Being 'ordinary'
- Self-directed support
- Having a voice
- Choice about where I live
- Choice about who I live with
- Choosing who supports me
- Choosing how my needs are met
- Being able to take risks
- Being respected and having rights
- Being in control
- Being an equal citizen

Based on feedback from Regional Events held as part of Independent Living Review

7. Independent living is about having choice and control over the assistance or equipment needed to go about our daily lives. Everyone needs assistance or equipment of some kind. In our society, for example, we do not draw water from the river. Instead, we rely on water companies to provide the kind of assistance and equipment necessary and to deliver it in ways which give us choice and control (the ability to turn on the tap to get the water we need).

2 Prime Minister's Strategy Unit, Cabinet Office, (2005), 'Improving the Life Chances of Disabled People'.

8. However, many people with physical and/or sensory impairments, learning disabilities, mental health support needs, long-term health conditions and/or who experience frailty often associated with very old age, have needs for assistance which are in addition to those of the general population. Some of these additional needs are the result of disabling barriers, such as the need for a taxi if public transport is inaccessible. Other needs are integral to having a particular impairment or condition such as a lightwriter for someone who does not use speech, or assistance with daily living for someone who has dementia.
9. In the past, these additional needs for assistance or equipment have been met in ways which did not give people choice and control. Instead, others decided on behalf of disabled people how assistance should be provided and this generally led to segregation and social exclusion. For many disabled people, particularly older people and those with significant levels of cognitive and/or communication impairments, this is still too often the case.
10. It is important to recognise that anyone, whatever their level of impairment, can express preferences and therefore express choices about how their needs should be met. Our aim is to ensure that all disabled people, including those with significant learning disabilities or other forms of cognitive impairment (including dementia), are enabled to have choice and control over how their support needs are met.

Independent living is a goal for all disabled people

Laura is 81 years old and has been living on her own since her husband died three years ago. She is having increasing problems with her short-term memory which has meant that she has sometimes left the bath running, the gas on, and forgotten to keep appointments with friends and with her General Practitioner (GP). Her daughter lives 150 miles away and on her last visit to her mother was worried enough to ring up social services.

An effective Independent Living Strategy will mean that Laura would have prompt access to health and support services, which would take a holistic and preventative approach to her needs. She would be supported to live where she chooses, and have choice and control over the type of support provided. She would also have easy access to information and advice to help her make choices and plan for the future, and – should she need it – access to independent advocacy.

Vision and aims of the Strategy

11. The Government is committed to every locality having a single community based support system which focuses on all aspects of what people need to maximise health and wellbeing and to participate in family and community life. The right to self-determination will be at the heart of this reformed system.
12. Independent living is an important part of enabling disabled people of all ages to fulfil the roles and responsibilities of citizenship. Without choice and control, disabled people face barriers to participating in, and contributing to, society. The Government is therefore committed to enabling disabled people to have choice and control over the support they need to live their everyday lives. The fulfilment of this commitment will be a vital part of delivering the 2025 vision of full and equal citizenship set out in ‘Improving the Life Chances of Disabled People’.³
13. The aim of the five year Independent Living Strategy is that:
 - disabled people, (including older disabled people), who need support to go about their daily lives will have greater choice and control over how support is provided
 - disabled people (including older disabled people) will have greater access to housing, transport, health, employment, and leisure opportunities and to participation in family and community life.
14. Progress towards this vision and aims will be measured and reported on annually to the Life Chances Ministerial Group. The framework for measuring progress is set out below and further details are given in **Annex C**. Additional mechanisms for monitoring progress are proposed in Chapter 4 and we are inviting views on these. If satisfactory progress is not made on delivering independent living, the Government will review the need for new legislation.

3 Prime Minister’s Strategy Unit, Cabinet Office, (2005), ‘Improving the Life Chances of Disabled People’.

VISION AND OUTCOMES FRAMEWORK FOR INDEPENDENT LIVING STRATEGY

Vision: All disabled people will have the same choice, control and freedom as every other citizen and any support is based on individuals' own choices and aspirations

Greater choice and control

Greater access to housing, transport, health, employment, education and leisure opportunities

Participation in family and community life

NB: The outcome measures set out below are examples only. Full details of measures are given in Annex C

Choice and control (PSA 15, 19)	Local councils' performance on the seven health, and social care outcomes (CAA)	Satisfaction of older people with home and neighbourhood (PSA 17)	Gap in employment rates between disabled and non-disabled people (ODI Life Chances Indicator PSA 8)	Employment/independent living and mental health or learning disability (PSA 16)	Perception of dignity and respect when accessing public services (PSA 15)	Participation in cultural, sporting and leisure activities (ODI Life Chances Indicator)	Disabled parents' access to childcare (ODI Life Chances Indicator)
Provision of advice, assistance and support (PSA 19)	Numbers accessing self-directed support (DH DSO)	Disabled people in poor housing conditions or housing not suited to their needs (ODI Life Chances Indicator)	Disabled individuals living in income poverty (ODI Life Chances Indicator)	Experience of using public transport (ODI Life Chances Indicator)	People supported to be in control of their condition (DH DSO)	Participation in public life (PSA 15)	Outcomes for those in receipt of housing support (Supporting People outcomes framework)
Independent living (PSA 17, 18)						Volunteering levels (ODI Life Chances Indicator)	

**PSA = Public Service Agreement
DSO = Departmental Strategic Objectives**

CAA = Comprehensive Area Assessment



2. Independent Living Strategy

Chapter 2 – Independent Living Strategy

Introduction

1. We set out below our detailed five year Strategy for making progress on independent living. Throughout the Strategy, we provide case study illustrations, based on real life examples. Each section concludes with a summary of what difference we would expect to see if the Strategy achieves the vision set out in Chapter 1. The detail of how we will measure whether this progress is achieved is given in **Annex C**. Not all the differences identified can be measured using currently available data and **Annex C** also identifies these gaps.

Timescales and lead departments are shown in **Annex B**.

2. The Independent Living Strategy has clear links to a number of strategies which the Government has recently published. These include ‘Aiming high for disabled children: better support for families’ (see section 10)⁴; ‘Putting People First: A shared vision and commitment to the transformation of Adult Social Care’ (see section 7)⁵; and the ‘Lifetime Homes: Lifetime Neighbourhoods: A National Strategy for Housing in an Ageing Society’⁶ (see section 3). The Independent Living Strategy also has clear links to the cross-government service transformation agenda, as set out in the Service Transformation Agreement which was published alongside the new Public Service Agreement (PSA) framework in the Comprehensive Spending Review in October 2007⁷. This Service Transformation Agreement has as its theme the accessibility of public services and encourages all parts of Government to join up those services around the needs of users. The life

4 Department for Education & Skills, Her Majesty’s Treasury, (2007), ‘Aiming high for disabled children: better support for families’.

5 Department of Health, (2007), ‘Putting People First: A shared vision and commitment to the transformation of Adult Social Care’.

6 Communities and Local Government, (2008), ‘Lifetime Homes: Lifetime Neighbourhoods: A National Strategy for Housing in an Ageing Society.’

7 http://www.hm-treasury.gov.uk/media/B/9/pbr_csr07_service.pdf

Chapter 2 – Independent Living Strategy

course approach of the Independent Living Strategy is consistent with the Agreement's focus on the grouping of services in ways which are meaningful to people and its vision is for Government to develop ways to offer integrated services, which respond directly to the tasks different groups of people and individuals face in their daily lives and which offer a timely response to immediate needs.

1. Communication activities to support the delivery of independent living

Rationale and intended outcomes

A clear message from disabled people is that there is too big a gap between national policy aims and local implementation. If disabled people are to have choice and control over the support they need, a major cultural shift is required. Creating a shared understanding of first, the principles of choice and control, and second, how to marshal resources to deliver independent living, will therefore be a key part of delivering the aims of our five year Strategy.

It is expected that the impact of communication activities will be reflected in outcome indicators which measure choice and control, and specifically through progress on delivering PSA Delivery Agreement 15: 'Address the disadvantage that individuals experience because of their gender, race, disability, age, sexual orientation, religion or belief'. The implementation of the communication strategy will itself include measuring reach and impact of the various activities.

Hussain is 81 and has multiple impairments. He lives with his son and his family. Hussain has always been active and involved in family and community life but, in the last few years, his support needs have increased. He has been in and out of hospital and his memory is not what it used to be. He does not speak English. It has been suggested that he should go into a residential home. Hussain and his family want him to live with the family but none of them have heard of the concept of independent living. He and his family feel that local services are not culturally sensitive and that they are dependent on volunteers from their community to provide support and translation. Hussain has needs related to his housing conditions, mobility impairment and his health. He wants to remain involved in family and community life.

An effective independent living strategy will mean that information is available to Hussain and his family about **what independent living means and how he can be helped to have choice and control in his life**. Hussain would have access to peer and advocacy support to enable him and his family to put in place the equipment, adaptations and culturally appropriate support so that he can regain his involvement in his family and community.

Commitments

1.1 **Awareness building and attitude changing programme to create support for an independent living approach**

The Office for Disability Issues (ODI) will, with support from other government departments and other identified organisations, develop an awareness building and attitude changing programme in order to create support for an independent living approach. This programme will be based on audience insight. Research will be undertaken to determine the best approach to make a real difference to existing practice.

1.2 **Communicate independent living messages to practitioners**

The first phase of this Strategy will start in 2008/09, (following the promotion of the five year Strategy itself in 2007/08), and will focus on practitioners. It will review existing guidance and training to those delivering health, housing, social care, and employment services used by disabled people (these elements are contained elsewhere within the Strategy). The communication task is to tailor messages to these audiences to promote an independent living approach, this will include paying attention to the relevance and meaning of independent living for older disabled people. The ODI communications and external relations teams will work with communications teams in other government departments to identify opportunities where independent living messages can be communicated through existing programmes of work, this will include engaging internal communications teams as well as external.⁸ It is expected that this part of the programme will continue until 2010/11.

1.3 **Communication materials for practitioners**

The ODI will develop a suite of communication materials for practitioners in partnership with other government departments and disabled people, including paying particular attention to those working with older disabled people. These will be used to promote the need to take an independent living approach. These materials will be made available to other departments and organisations, (for example, Social Care Institute for Excellence (SCIE), Commission for Social Care Inspection (CSCI), the Healthcare Commission, Skills for Care and Development, Skills for Health and the General Social Care Council), to be distributed through their existing networks. These materials will provide information and guidance within the context of practitioner bodies developing their disability equality schemes, so as to ensure that the burden on practitioners is not too great, and to ensure that this is part of their overall approach to disabled people. The materials will also highlight to practitioners the benefits of taking this approach (based on the research referred to in 1.1 above).

8 Departments include: Department of Health (DH), Department for Children, Schools and Families (DCSF), Communities and Local Government (CLG), Department for Transport (DfT), Cabinet Office and Department for Work and Pensions (DWP), and the Government Equalities Office.

1.4 **Communicate independent living messages to users and potential users of services and to carers**

The second phase of communication activities will focus on disabled people who are users or potential users of public services and will be implemented once the practitioner audience is fully engaged. The ODI will facilitate discussion with relevant government departments, the Equalities and Human Rights Commission (EHRC), age organisations, disability organisations, and carers and advocacy organisations to determine the best approach to reach the full range of disabled people. The ODI will also work with the DWP to ensure that messages on independent living are incorporated in communications to carers.

1.5 **Focus on the specific communication needs of different groups of disabled people, including black minority ethnic communities and older people**

This second phase will also look at the need for communications to groups who are known to require a bespoke approach to ensure their engagement, including people with a learning disability, people with mental health conditions, disabled people from black and minority ethnic (BME) communities, and older and younger disabled people.

Five years from now:

This will be different...

Government will have a co-ordinated and consistent approach to the promotion of independent living for all groups of disabled people.

We will know this because...

A common understanding of what independent living means will be evident across Government and the Government Offices for the Regions in the context of housing, employment, education, transport, health and social care policies.

This will be different...

People working to commission and deliver local services used by disabled people, (including older disabled people), will have a better understanding of the meaning and importance of choice and control/self-directed support, and of commissioners' and practitioners' role in enabling independent living. They will have the tools that enable them to take this approach.

We will know this because...

There will be an increase over time in the proportion of disabled people saying they have choice and control over the support needed to go about their daily lives.

Note: Details of how progress will be measured are given in **Annex C**.

2. Action and Learning Sites and Regional Initiatives

Rationale and intended outcomes

The work of the Independent Living Review has demonstrated that there is a need to further strengthen the evidence-base for investment in independent living. We commissioned two literature reviews concerning the evidence for investment in independent living. These were: 'Better outcomes, lower costs, Implications for health and social care budgets of investment in housing adaptations, improvements and equipment: a review of the evidence'⁹; and, 'The costs and benefits of independent living'¹⁰. These reports are published on the ODI website¹¹.

9 Office for Disability Issues, University of Bristol, (2007), 'Better outcomes, lower costs, Implications for health and social care budgets of investment in housing adaptations, improvements and equipment: a review of the evidence'.

10 Office for Disability Issues, SQW Consulting, (2007), 'The costs and benefits of independent living'.

11 <http://www.officefordisability.gov.uk/publications/>

In addition, we commissioned a demographic analysis of ageing and independent living.

A specific focus is needed on: the role of advocacy, support and brokerage services as assessment and care management systems develop to take account of the personalisation agenda; how to promote choice and control for older people in, or about to move into, residential and nursing care; and, the need for advocacy support amongst people who are particularly vulnerable to losing choice and control (see section 8.2).

Our policies are intended to both, strengthen the evidence-base to inform future policy development and investment, and demonstrate how to use resources to better promote choice and control.

Commitments

2.1 Scoping work will be developed for two initiatives:

- Action and Learning Sites to demonstrate redeployment of resources from professional assessment and care management to user-led support, advocacy and brokerage
- a regional initiative to demonstrate how we can invest in independent living for older disabled people in residential/nursing care or at risk of moving into residential/nursing care.

2.2 Following from this scoping exercise, decisions will be made concerning the design of, and investment in, the Action and Learning Sites and Regional Initiatives (see also section 8.2).

3. Housing

Rationale and intended outcomes

Investment in improved housing opportunities and conditions for disabled people makes economic sense and the availability of suitable housing lies at the heart of ensuring that disabled people, of all ages, are supported to live at home or move to alternative accommodation of their choice. Our policies in

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this area aim to empower disabled people through the provision of advice and information, and to maximise their housing opportunities by influencing provision of, and access to, suitable housing.

Progress on improving housing opportunities and conditions experienced by disabled people will be measured by indicators on satisfaction with services, data on housing conditions and tenure, and the numbers of properties built to the Lifetime Homes standard.

Michael is 45 and married to Rachel. They have three children aged between 4 and 13. Two years ago Michael had a serious road accident which left him with a mobility impairment and he now uses a wheelchair. The family house is not wheelchair accessible and Michael and Rachel have experienced considerable difficulties in getting the advice and information they need in order to adapt their current home or find an alternative property that is suitable. In the meantime, Michael is confined to the downstairs of their house and the living room has been turned into a bedroom, with a commode. He can only have a bath by visiting the local day centre. The family is finding it increasingly difficult to cope in such circumstances.

An effective independent living strategy will mean that Michael and Rachel would have **prompt access to the advice and information** they need about their options in terms of **making adaptations** to their current property, and that there would be **more homes built to the Lifetime Homes standard**.

Commitments

3.1 Increase the provision of housing advice and information

There is a need for a single, joined-up approach to independent information and advice on housing and connected issues, including finance and care options. This will enable older people, (including older disabled people), to make active and informed decisions about their housing options, like any other group.

Communities and Local Government (CLG) will develop a new national advice and information service for older people from 2008/09, working across Government and with external partners. This will include a one stop shop telephone and website service for housing, finance and care information and advice. The service will be sensitive to the needs of excluded groups,

including people whose first language is not English, and people with sensory impairments. Initially the service will operate at a national level, but it will be linked into local authority, home improvement agency and other local voluntary and community sector services. The new service will build on existing advice and information services within a trusted network. We will also pilot and evaluate improved local housing options services linked to the national service.

In the longer-term, we will consider how housing information and advice services can become proactive rather than simply responsive. In particular, there is a need for better identification of excluded older people before they experience a crisis, so that housing related information and support can be tailored and targeted more effectively (see 3.6 below).

We will also consider whether people can be targeted with housing options information and simple ways of auditing their homes at key transition points such as retirement or onset of ill health.

3.2 Update the Lifetime Homes standard and make it an essential element in the Code for Sustainable Homes

CLG will update the Lifetime Homes standard, following the development of a new British Lifetime Homes standard which will create a clear definition of the standards required and the guidelines to be followed by designers. The Lifetime Homes standard will become mandatory at decreasing levels of the Code for Sustainable Homes over time, encouraging a broader uptake. CLG published a consultation paper, 'The future of the Code for Sustainable Homes – Making a Rating Mandatory' in July 2007 alongside the Housing Green Paper¹². This recommended that the Code includes the Lifetime Homes standard in order to achieve a rating as follows:

- Level 6 in the code in 2008
- Level 4 and above by 2010
- Level 3 and above in 2013.

12 Communities and Local Government, (2007), 'The Future of the Code for Sustainable Homes – Making a Rating Mandatory'

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Adherence to Lifetime Homes standard will be mandatory for all public sector funded housing by 2011.

3.3 The Lifetime Homes standard and the private sector

The Government is optimistic that the private housing sector will respond positively to the need for Lifetime Homes and proceed to incorporate the standard as they modify their existing designs to meet the move towards Zero Carbon Housing in 2016. CLG has set a clear target for the construction of all new housing to the Lifetime Homes standard by 2013, with a commitment to review progress against this target by 2010.

3.4 Accessible Housing Registers

Some local authorities and housing associations already maintain an Accessible Housing Register, a database of properties designed or adapted for use by people with access needs. These are intended to ensure that disabled people are housed appropriately and enable the best use to be made of purpose built or adapted stock. CLG is promoting a new approach to the letting of social housing which gives new and existing tenants more of a say in where they live. The so-called Choice-Based Lettings approach allows prospective tenants to see the full range of properties available – which are openly advertised – and to apply for properties which meet their needs. Advertisements contain property information, including any accessibility features, thereby enabling people with access needs to consider whether the vacancy is appropriate to their needs. CLG has set a target for all local authorities to have adopted Choice-Based Lettings by 2010 and is also encouraging local authorities and housing associations to make information available on the accessibility of the social housing stock through the National Register of Social Housing (NROSH). CLG will continue to encourage the adoption of Accessible Housing Registers through, for example, forthcoming statutory guidance on Choice-Based Lettings; and, will support the dissemination of good practice models, such as the London Accessible Housing Register.

When considering the role of Accessible Housing Registers, any implications of differential housing opportunities across different minority ethnic groups will be considered.

3.5 Investment to provide rapid repairs and adaptations services

CLG will develop a new nationally funded rapid repairs and adaptations services from 2009 to ensure that disabled people, (including older disabled people), will be able to get minor adaptations and repairs done when they need it. This new funding will significantly expand coverage of handyperson services nationally, help to build capacity within the sector, and develop service standards. We will work with local authorities, health sector service commissioners and other partners, including home improvement agencies, to ensure that the delivery of handyperson schemes is linked into related services, including security, fire safety, energy efficiency services, major adaptations, health and care.

3.6 Early intervention

Research, by the King's Fund that CLG commissioned, shows that early intervention can be far more effective for older people, providing it reaches the right people. The study examined the feasibility of using predictive risk modelling with routinely collected data to accurately identify people a year before a care crisis. This has already been successfully trialled with hospital admissions, but not considered in relation to preventable and costly social care crises.

For the first time anywhere, we will develop and pilot the technology using predictive risk modelling to identify individuals who are at risk of both health and care crises a year early. This technology will provide a tool for developing the business case for preventative investment showing pro-rata savings to both health and care across a local population. It will also help with predicting future population needs. For this reason, there may be significant applications for this in the areas of resource allocation, commissioning and performance management, as well as simply to identify individuals for preventative services.

3.7 Disabled Facilities Grant

The Disabled Facilities Grant (DFG) enables around 37,000 disabled and older people each year to continue to live independently in their own homes. Central Government funding for DFG has more than doubled since 1997 from £57 million to £121 million this year. In recognition of the programme's important contribution to aiding independent living, from 2008/09 Government funding will increase by 20 per cent to £146 million, seven per cent in 2009, and a further six per cent in 2010.

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The Government recognises that there have been significant developments in housing and independent living over recent years and the programme is in need of modernisation. The key challenge is to modernise the DFG programme to make it more responsive to individuals' needs.

A public consultation on the Government's proposals to improve the DFG programme was held between 18 January and 13 April 2007.

In response to the consultation CLG has proposed to make changes to the DFG system. The main proposed changes are:

- increasing the maximum grant limit
- improving the means test process and changing it so that working tax credit and child tax credit are not counted as income
- speeding up and simplifying the system so that authorities can deliver small scale adaptations
- creating greater flexibility, which would enable DFG to be used for associated purposes such as moving home, where this is a more appropriate solution.

3.8 Supporting People

The Supporting People programme funds local authorities to provide services which help vulnerable and older people, including over 450,000 disabled people, to live independently.

Supporting People programme funding can be used to contribute towards costs, such as the employment of a home improvement agency to oversee all aspects of having a home adapted, or, it can fund services which give a disabled person the confidence to continue to live independently and reduce the likelihood of them moving into residential care. Supporting People programme funded services also work with social care services for those with more intensive needs, within supported accommodation, and, increasingly, delivering support into individuals' own homes.

Five years from now:

This will be different...

Older disabled people in any part of the country will be able to easily access housing advice and information.

Disabled people will experience increased housing opportunities and will be more likely to live in housing which is suited to their needs.

We will know this because...

Housing advice and information will be available in appropriate forms and formats, and accessible to older disabled people.

There will be an increase in homes built to Lifetime Homes standard, the numbers of vulnerable people achieving independent living and in those supported to live independently by social services.

There will be a decrease in the numbers of disabled people living in poor housing conditions and in housing which is not suitable to meet their needs.

Note: Details of how progress will be measured are given in **Annex C**.

4. Transport and mobility

Rationale and intended outcomes

Transport and mobility have a major influence on most people's lives and the absence of suitable transport can prevent disabled people from participating in society. Improvements have been made in relation to disabled people's rights in the use of transport. Progress has also been made in terms of increasing the accessibility of public transport, and more progress will be made over the next 15 years. The Independent Living Strategy is an opportunity to consolidate progress made in the areas of training, information, and accessibility. It is also an opportunity to consider the action required to enhance the mobility opportunities of people for whom public transport is not likely to be the best way to meet their needs.

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We would expect progress in this area to be reflected in survey evidence that more disabled people are using public transport; improvements measured by the Accessibility Indicator in the Local Area Agreements framework; favourable trends in complaints about transport providers; and, in the longer-term, improvements in the travel and mobility experiences of disabled people as measured by the disability longitudinal survey.

Geoff has been diagnosed with macular degeneration and has had to give up driving because of the deterioration in his eyesight. Increasingly, he lacks confidence to go outside his home and, as he lives alone, he relies on his family and neighbours to do his shopping, collect his pension, and so on. He misses going to the bowling club and has also stopped attending meetings of the Parish Council, where he had been an active member. His neighbour is worried that Geoff seems depressed and is not eating properly.

An effective independent living strategy will mean that, on diagnosis, Geoff would have been provided with advice and information about his condition, about how to obtain assistance and equipment, and about **transport and mobility options**. He would have had access to expertise in how to live with macular degeneration (from both professionals and other people with the same condition). He would have **access to a local community transport service with drivers who are sensitive to his needs**.

Commitments

4.1 Evidence-based strategies for enhancing personal mobility options and transport choices for disabled people

The Department for Transport (DfT) will develop evidence-based strategies for enhancing the personal mobility options and range of modal transport choices for disabled people. This will include:

- improved information about, and access to, door-to-door transport (Dial-a-Ride, community transport), through enabling disabled people to make more informed decisions and choices, for example through an improved A2B portal and exploring possible links to the Transport Direct Portal

- appropriate use of personal forms of transport including powered wheelchairs and mobility scooters
- appropriate use of cars, for example by implementing recommendations arising from the current strategic review of the Blue Badge Scheme, and increasing the quantity and quality of information and advice at assessment centres for disabled car users (including signposting to other options).

4.2 Training of transport providers

The DfT will continue to encourage transport operators to offer disability awareness training and to improve the standards of training already offered by:

- promulgating best practice
- working towards wider formal accreditation of awareness training
- disseminating Disability Rights Commission (DRC) guidance on implementing Part 3 of the Disability Discrimination Act (DDA).

4.3 Information and confidence training for disabled people

The DfT will develop and deliver a strategy for providing information and confidence training for disabled people, so that they are enabled to access and use public transport. This strategy will:

- promote the benefits of travel training amongst stakeholders through promotion and dissemination of first, the report on existing travel training approaches and good practice in current programmes, 'Travel Training Schemes - a review of travel training schemes in England'¹³ and second, materials and tools by government departments and umbrella bodies.
- take forward findings from evaluation of DRC's GOJO campaign.

13 Department for Transport, (2007), 'Travel Training Schemes - a review of travel schemes in England'.

4.4 Local transport plans and accessibility planning

The DfT will work with local authorities to ensure accessibility planning is reflected in Local Transport Plans and Local Area Agreements through:

- good practice guidance or case studies
- continued development of future accessibility planning (including suitable indicators).

4.5 Stakeholder engagement including a focus on harder to reach groups

The DfT will work to improve engagement with those who are influenced by, or have an influence on, the development and implementation of transport policies. This includes socially excluded individuals, particularly hard to reach groups representing race, faith, gender and age organisations, and people responsible for delivering accessibility and equality policy (for example, local authorities and the voluntary sector). This engagement with stakeholders will involve consulting them on defining and developing policy, working with them to deliver policy, and informing them of changes in policy.

Five years from now:

This will be different...

Disabled people will have improved access to information and travel training, so they can make informed choices about using public transport and about alternatives when public transport is not suitable for them.

Disabled people will experience transport providers as being helpful and facilitating their access.

We will know this because...

Information will be available from a range of sources and in accessible formats.

There will be an improvement in the percentage of disabled people who say that they have been treated fairly by services.

This will be different...

It will be easier for disabled people to use public transport.

We will know this because...

More disabled people will be using public transport.

Note: Details of how progress will be measured are given in **Annex C**.

5. Health

Rationale and intended outcomes

There is considerable evidence that disabled people – across all impairment and age groups – experience unequal access to healthcare and inequalities in health. In addition, for many people, management of a long-term health condition is key to their quality of life and participation in society. Our policies in this area seek to build on existing and current work, and the opportunities presented by the Disability Equality Duty (DED), to enhance understanding of health services' contribution to independent living. Our aim is to enable disabled people to have choice and control over their non-acute health care needs, and to further promote self-management of long-term conditions. Self-care/management programmes also play a key role in supporting the national strategy to assist people to remain in employment.

In addition, our aim is that – where people have continuing health care needs – these needs should be met in ways which deliver choice and control, and which enable a holistic and joined-up service response.

We would expect progress in this area to be reflected in more equitable access to health services. We would also expect increasing numbers of people to be self-managing their long-term conditions and to be reporting that they are empowered to have choice over how their non-acute health care needs are met.

Commitments

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

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

The programme will consist of three key elements:

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

5.2 Expert Patients Programmes and self-management support: increasing take-up of existing programme and developing new approaches that work for disabled people (including older disabled people)

The DH will increase the profile of, and access to, self-management techniques and approaches for disabled people with long-term, chronic and degenerative conditions. A key success factor of this initiative will be an enhanced role of/for disabled and older people's organisations, including user-led organisations and peer support initiatives, (such as the Expert Patients Programmes), in supporting disabled people to maintain their health and improve their access to, and experiences of, healthcare. Where technical and specialist clinical interventions are an important feature of increasing choice and control, (for example, Assistive Technology, in stroke care and heart disease programmes), the role of self-management and Expert Patients Programmes needs further promoting and developing.

Access to self-management and Expert Patients Programmes will be increased through:

- increasing the number of locally based self-management programmes, including programmes targeted at people with specific conditions, and assistance aimed at supporting disabled people to attend such programmes. We will ensure that these programmes provide appropriate opportunities for BME disabled people in terms of both, their access to programmes generally, and ensuring that programmes targeted at specific conditions include those with particular relevance to some BME communities (for example, sickle cell disorder and thalassaemia)
- increased access to user and peer-led support, both to attend self-care programmes, and to manage long-term conditions and health care support needs associated with disability/long-term conditions. This includes increased availability of accessible information about local self-management/ Expert Patients Programmes and the use of information prescriptions and signposting to user-led organisations by frontline practitioners and NHS provider organisations. We will ensure that information gets to BME communities and that peer support is available from within BME communities

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- increased access to health trainers and advocacy support to enable disabled people, who need support to self-manage, to participate in local programmes. We will ensure that health trainers and advocacy support are drawn from BME communities and that BME disabled people have equal access to such support
- encouraging PCT commissioners to make self-care/management explicit in contracts with providers of long-term care services and the range of support available to people with long-term conditions
- monitoring the uptake and effectiveness of self-management programmes and initiatives run and attended by disabled people. The new PSAs and commissioning frameworks will facilitate this, as will both: more explicit references to the provision of, and increased uptake of, self-care/management programmes in contracts with providers of long-term conditions treatment; and, support and associated health interventions (for example, physiotherapy, speech and language therapies, talking therapies) – as outlined above. Commissioning frameworks for self-care/management programmes and contracts for health interventions such as physiotherapy, speech and language therapies, and talking therapies, should make explicit reference to means of enabling access for BME disabled people. The ODI will work with the Government Equalities Office to improve data on BME disabled people in the monitoring of PSA Delivery Agreement 19 Ensure better care for all, Indicator 5: ‘People with long-term conditions supported to be independent and in control of their condition’.

5.3 Choice and control and continuing healthcare

Our aim is that – where people have continuing health care needs – these needs should be met in ways which deliver choice and control, and which enable a holistic and joined-up service response.

In order to move forward on this aim the DH will:

- set up a working group, with strong user representation
- scope good practice and test out the information gathered with lawyers
- publish good practice guidance.

Five years from now:

This will be different...

Disabled people will experience positive, enabling attitudes, behaviours and support from NHS staff in order to access the full range of health care information, advice, treatment and support that they need.

Disabled people will have increased choice, control and flexibility over their non-acute and continuing health care.

Disabled people with specific conditions will be able to access information, advice and treatment options, including peer advice/support as well as support from trained professionals with specialist knowledge.

Disabled people will have increased access to support to self-manage long-term conditions.

We will know this because...

This will be evident from levels of complaints and from inspection activities.

Increasing numbers of disabled people will be reporting that they have choice and control over the support they need to live their everyday lives.

Examples of good practice illustrating what works, how and what makes it happen, and support will be widely available for NHS staff and disabled people.

A greater number and range of third sector organisations will be commissioned to provide information, advice, advocacy and self-care/management programmes.

There will be increasing numbers of people with long-term conditions supported to be independent and in control of their condition.

Note: Details of how progress will be measured are given in **Annex C**.

6. Employment and economic wellbeing

Rationale and intended outcomes

People's lives do not divide neatly into different policy areas and many experience a range of barriers to getting, keeping, and progressing in employment, some of which relate to the work situation but others do not.

From April 2008, Pathways to Work support will be available across Britain. This will give more disabled people access to the Choices programme of employment support, including the Condition Management Programme and Return to Work Credit. From October 2008, we will introduce a new benefit, the Employment and Support Allowance (ESA). This will replace incapacity benefits for new customers and will offer a new unified benefit which, together with Pathways to Work, will help disabled people back into work. In addition, we are developing a National Strategy for Mental Health and Work, to ensure a co-ordinated response across Government to the challenges faced by people of working age with mental health conditions and to improve their employment chances. 'Valuing people now: from progress to transformation – a consultation on the next three years of learning disability policy'¹⁴ sets out the Government's commitment to ensuring that more people with learning disabilities are in paid, real jobs.

Important progress is being made to support people to enter employment, and more needs to be done to address the barriers to keeping a job when someone acquires an impairment or when an existing impairment or condition deteriorates. Our policies under this heading also seek to ensure that current benefit and charging systems, and recent reforms, do not create any unnecessary barriers to independent living. There are also policies in the section 'Young disabled people in transition to adulthood' which will make a contribution to disabled people's employment rates and economic wellbeing.

14 Department of Health, (2007), 'Valuing people now: from progress to transformation – a consultation on the next three years of learning disability policy'.

Progress in these areas would be reflected in reductions in the gap between the employment and volunteering rates of disabled and non-disabled people, the numbers of young disabled people who are not in education, employment or training, and in the numbers of disabled people and children of disabled parents living in poverty. There will also be an improvement in the evidence-base for the contribution of the benefit system to independent living.

Lee is 25 years old and has fluctuating mental health support needs which have an impact on all aspects of his life. He is frequently absent from work and, when he does come to work, he is often under the influence of alcohol. He is in debt, has rent arrears and faces possible eviction. He was recently bereaved and is also at risk of losing shared parental responsibility for his son.

An effective strategy to deliver independent living will mean that Lee **is able to remain in paid employment and has choice and control over the assistance he needs**. It will mean he has access to: information, advice and advocacy concerning the range of issues he is facing; assistance with developing a support network, including peer support; mental health services which meet his specific health needs; reasonable adjustments and understanding from his employer; and access to further training and development opportunities. Such services will be delivered in ways which promote Lee's choice and control over the assistance he needs.

Commitments

6.1 **Action to improve specialist employment support services for disabled people**

The DWP has launched a public consultation 'Helping people achieve their full potential: Improving Specialist Disability Employment Services'. The DWP is proposing reforms that would make its specialist employment focused services better able to meet the needs of individual disabled people. The aim is to have a greater focus on those disabled customers who need specialist support, improving the quality and flexibility of these services. The consultation recognises that some people need long-term support in employment.

6.2 Cross-government national strategy aimed at enabling people to remain in employment when they acquire an impairment or their condition worsens

The DWP along with the ODI will lead the development of a cross-government national strategy aimed at enabling people to remain in employment when they acquire an impairment or long-term health condition, or when an existing impairment or condition worsens/fluctuates. This development work will include identifying ways of delivering the strategy and associated costs. The strategy will pay particular attention to the experiences of BME disabled people, for example, looking at the implications of: the employment profile of different minority ethnic populations; their impairment/health profile; and, the co-existence of discrimination on the basis of race and of disability.

6.3 Increase access to volunteering opportunities for disabled people

The Office of the Third Sector (OTS) will lead work to increase disabled people's access to volunteering opportunities by:

- extending for a further year Goldstart – a project aimed at spreading best practice in mentoring and volunteering – and Volunteering for All, which funds targeted recruitment campaigns for volunteers in priority groups
- funding a combined programme looking at best practice in volunteering and creating an evidence-base, (part of this programme will be focussed on improving access to volunteering for disabled people).

The OTS will identify any particular issues for BME disabled people in terms of best practice, and ensure that the evidence-base includes how to address specific barriers experienced by BME disabled people. The ODI will work with the Government Equalities Office to monitor levels of volunteering amongst BME disabled people, as measured by the Citizenship Survey.

6.4 Participation in public and civic life

We will change benefit reclaim processes and, if required, regulations to address disincentives and enable participation in public and civic life. The ODI will work with the Government Equalities Office to monitor the involvement of BME disabled people in public and civic life, as measured by the Citizenship Survey.

6.5 Investigation of the impact of reforms to the benefit system, employment support programmes and charging policies within adult social care

The ODI will carry out an investigation of the combined impact of reforms to the benefit system (ESA, Housing Benefit), employment support programmes, and charging policies within adult social care, to establish whether their combined impact promotes disability equality. This investigation will be carried out after the disability equality impact assessments of each reform.

6.6 Charging and residential care

We will consider amending guidance on charging for residential care, (in line with current guidance on charging for community services), to remove the current disincentive to paid employment.

The DH will be considering this proposal early in 2008, along with other proposals to amend the Charging for Residential Accommodation Guide (CRAG).

6.7 The role of Disability Living Allowance (DLA) and Attendance Allowance (AA) in supporting independent living

The DWP will evaluate the current and future role of DLA and AA in supporting independent living. In doing this we will examine the feasibility of exploring BME disabled people's experiences, both in terms of their access to DLA and AA, and their experience of the principles and practice of independent living.

Five years from now:

This will be different...

More disabled people will be helped into employment and employees who acquire an impairment or, whose existing impairment/condition worsens, will be more likely to remain in employment.

We will know this because...

There will be a narrowing of the employment gap between disabled and non-disabled people.

There will be fewer disabled people, and children of disabled parents, living in poverty.

This will be different...	We will know this because...
There will be an increase in access to volunteering opportunities for disabled people.	More disabled people will participate in volunteering activities.
Disabled people will experience fewer disincentives to take public appointments.	There will be an increase in numbers of disabled people taking up public appointments.

Note: Details of how progress will be measured are given in **Annex C**.

7. Personalisation, choice and control

Rationale and intended outcomes

The Government's policies under this section relate to the Life Chances commitment to independent living and the vision set out in the White Paper¹⁵ 'Our health, our care, our say: a new direction for community service' that, 'there will be a radical and sustained shift in the way in which health, social care and other community services are delivered – ensuring that they are more personalised and that they fit into people's busy lives. This requires that people have a stronger voice so that they are the major drivers of service improvement.' Our vision and that of our partners is set out in 'Putting People First: a shared vision and commitment to the transformation of adult social care'¹⁶. This document can be located on the DH website¹⁷.

15 Department of Health, (2006), 'Our health, our care, our say: a new direction for community service'.

16 Department of Health, (2007), 'Putting People First: a shared vision and commitment to the transformation of adult social care'.

17 http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_081118
Further details of the transformation grant linked to this are contained in LAC(DH)(2008)1 at http://www.dh.gov.uk/en/publicationsandstatistics/Lettersandcirculars/LocalAuthorityCirculars/DH_081934

This section of our Strategy sets out the general approach to delivering these commitments and makes some specific proposals. It is important to emphasise that these commitments to promote independent living are intended to benefit self-funders, as well as those who are eligible for state-funded social care.

Progress on delivering personalisation, choice and control will be measured by the performance framework, by data on fair treatment by services, and by data on the extent to which disabled people experience choice and control over the support they need to go about their everyday lives.

Steven is 25 years old and has autistic spectrum disorder and moderate learning disabilities. Three years ago he moved into a group home, run by a learning disability charity, but was very unhappy there and was eventually asked to leave because his behaviour was upsetting the other residents. At the same time he lost his part-time job at the local postal sorting office. He moved back to live with his parents and spends his days mainly watching television. His behaviour can sometimes be very challenging to live with. Both he, and his parents, want him to have a home of his own and to have something meaningful to do with his life.

An effective independent living strategy will mean that Steven is supported to live in his own home, to develop his talents and skills and to be part of a supportive network. Steven would have access to peer and advocacy support to enable him to manage his own money and to help him to find employment and improve the quality of his life.

Commitments

We will support the transformation of social care to deliver a system which will focus on timely, preventative, and high quality personally tailored services. We want everyone – whether they receive state-funded support or fund support themselves – to have maximum choice and control over the support services they receive. We will work with local authorities and key partners to help them deliver this. The long-term aim will be to ensure that every disabled person in receipt of social care and/or related funding has the opportunity to have choice and control over the state funding they receive.



The Government announced in the Pre-Budget Report 2007 that it will publish a Green Paper on reform of the care and support system. The Green Paper will consider issues around the long-term funding of care, with an emphasis on supporting independence, choice and control.

7.1 The social care modernisation programme aims to enable people to shape the services that affect their lives. We will promote:

- increased personalisation of support through, for example, individual budgets and direct payments
- a strategic shift towards investment in early intervention and preventative approaches through initiatives such as the Partnerships for Older People Projects (POPP)
- the development of user-led organisations (see 8.3 below)
- access to better support, information and advocacy so that people are able to navigate health and social care systems (see also 8.1 and 5.3).

7.2 We will work with In Control Total and ensure that this initiative is linked in with the five year Strategy, by the ODI representation on the National Steering Group and other methods.

7.3 We are committed to extending the scope of direct payments to those currently excluded from having a direct payment. Provisions to extend direct payments to those without capacity are included in the Health and Social Care Bill 2007/08. Following the passage of the Bill, and subject to Parliament, DH will issue Regulations and revise the guidance relating to the extension of direct payments, taking account of the interface with the Mental Capacity Act 2005.

Five years from now:

This will be different...

Disabled people will have greater choice and control over the support and/or equipment they need to go about their daily lives.

Individuals and their families (including self-funders) will have access to a range of high quality information and advice, advocacy and support brokerage.

Responses to disabled people's needs will be more personalised.

We will know this because...

Support and equipment will be more personalised and fit better into people's lives.

There will be an increase in information and advice, advocacy and support brokerage services.

People who need support in their daily lives will experience increased opportunities to participate in family and community life.

Note: Details of how progress will be measured are given in **Annex C**.

8. Support, information, advocacy and brokerage

Rationale and intended outcomes

Effective support, information, advocacy and brokerage services are a key aspect of enabling disabled people to make choices for themselves that might otherwise be made for them by other people. Our policy of transforming social care includes a commitment to a universal information, advice and advocacy service for people who need support in their lives.

Progress on the extent to which such services are available is expected to be reflected through the new performance framework. Progress on the Life Chances commitment that there should be a user-led organisation, modelled on existing Centres for Independent Living (CILs), in every locality by 2010, will be reported as part of the ODI annual reporting process.

Commitments

8.1 **Local organisations should consider the needs of disabled people within their community for support, information, advocacy and brokerage services**

As set out in ‘Putting People First: a shared vision and commitment to the transformation of adult social care’¹⁸, PCTs and local authorities are expected to develop integrated approaches to achieve specific outcomes for their local populations, including universal information, advice and advocacy. The new Performance Framework for Local Government expects local authorities and their partners to set ambitious cross-cutting targets within their Local Area Agreements which may include an approach to delivering independent living for their communities.

As part of the new performance framework, the Local Government and Public Involvement in Health Act 2007, will also require upper tier local authorities and PCTs to conduct a joint assessment of the health and social needs of their local community.

In addition, we will explore the ways in which inspection, the performance framework for local government, the National Improvement and Efficiency Strategy, and the DED can be used to support local organisations to develop Local Action Plans for the mapping and provision of support, advocacy, information and brokerage services, paying particular attention to the role of user-led organisations. Local organisations should consider co-ordinating their approach through the local strategic partnerships (LSPs).

18 Department of Health, (2007), ‘Putting People First: a shared vision and commitment to the transformation of adult social care’.

8.2 The need for advocacy support when disabled people are particularly at risk of losing choice and control

The ODI will undertake a scoping study to assist the development of research to assess the need for, and the costs and benefits of providing, independent advocacy in the following situations:

- when entry to residential care is a possibility
- during transition to adulthood
- when the children of disabled parents are subject to safeguarding procedures
- when disabled people are victims or alleged perpetrators of anti-social behaviour.

8.2.1 Subject to the findings of the study in 8.2, decisions will be made on commissioning research to assess the need for, and the costs and benefits of providing, independent advocacy in the above situations.

8.3 User-led organisations

'Improving the Life Chances of Disabled People'¹⁹ included a commitment that, by 2010, each local authority area should have a user-led organisation modelled on existing Centres for Independent Living. DH set up the User-Led Organisations project in 2006 to address this commitment. Achieving this is dependent on the initiative and commitment of disabled people across the country, this can be nurtured and encouraged, but not imposed. To support this, DH set up the User-led Organisations Development Fund of up to £850,000 in 2007-08, offering user-led organisations which meet the policy and design criteria developed by the DH, the opportunity to become a User-led Action and Learning Site. The design criteria are set out in the User-led Organisations policy published in September 2007²⁰.

19 Prime Minister's Strategy Unit, Cabinet Office, (2005), 'Improving the Life Changes of Disabled People'.

20 http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_078804

The emphasis is on user-led organisations themselves developing practical solutions locally, and sharing this with others.

8.4 Advocacy training

DH are funding a project to develop a National Advocacy Qualification. Service users have been involved in identifying learning outcomes which underpin the qualification and are also represented on the project's working group. The involvement of service users in delivering training is likely to be an important feature of the course.

Five years from now:

This will be different...

Individuals and their families (including self-funders) will have access to a range of high quality information and advice, advocacy and support brokerage.

We will know this because...

There will be an increase in information and advice, advocacy, support and brokerage services, including those provided by user-led organisations.

Note: Details of how progress will be measured are given in **Annex C**.

9. Older people

Rationale and intended outcomes

Many policies and initiatives exist which seek to improve quality of later life and older people's experiences of public services generally. However, for older disabled people it is still health and social care services that dominate discussions about support and assistance; and there is little focus on choice and control as defined in 'Improving the Life Chances of Disabled People'²¹. In addition, despite a wide body of work that now exists on healthy life expectancy, the prominent features of demographic change are generally presented in a pessimistic fashion.

21 Prime Minister's Strategy Unit, Cabinet Office, (2005), 'Improving the Life Chances of Disabled People'.

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The life course approach adopted by the Independent Living Strategy is essential, and one which needs to be embedded in the future implementation of agreed policies, as it is usually the same people who experience disadvantage and poor health in later life who have experienced disadvantage and poor health all of their lives.

Much more needs to be done to deliver a co-ordinated, strategic approach to investing in and embedding independent living for older disabled people both in older people and ageing strategies, and in policies focusing on disability and disabled people. Options for independent living offer potential cost effective solutions to enabling older disabled people to access the support they want and need, as long as it operates across a broad sphere of influence encompassing all government departments and all public services – including those delivered by the private and voluntary sectors. Stronger and more explicit connections are therefore needed between different transformational and whole system change programmes, for example, the work between the Transformational Government Programme led by the Pensions Service and the personalisation agenda led by the DH.

A key issue for older disabled people is how their voices are heard and experiences captured, given that they are often amongst the most excluded groups in society. Further attention needs to be given to how user-led initiatives and disability organisations take account of the diverse needs, experiences, voices and contributions of older people. Older people's forums, advisory groups and other influencing mechanisms also need to pay attention to how older disabled people are enabled to participate.

Margaret, who is 89 and lives alone in her own home, has Parkinson's disease and recently spent five weeks in hospital after breaking her hip. Now back home, she has lost a lot of confidence in her ability to move around, feels that the symptoms of her Parkinson's disease have worsened, and is experiencing panic attacks which are preventing her from resuming her involvement in her local church and community. She is worried about money because she has incurred additional expenses since coming home. Although she wants to see more of her family, they all live in other parts of the country.

An effective independent living strategy will mean that Margaret can once again be an active member of her community, in control of her health, her home and her financial affairs. It would mean that she had access to advice, information and support to look at all aspects of her needs and circumstances, and choice and control over deciding what her needs are and how best to meet them. She would receive prompt responses to her needs for an accessible and safe home environment and help with addressing the seemingly minor things which do not come under the heading of 'personal care', but which make a big difference (for example, help with going through her bills to keep on top of paying them, assistance to get out and about in her local community). She would also receive prompt responses to her health concerns and choice and control over how her condition is managed.

Commitments

Many of our commitments in other sections of this Strategy will benefit older disabled people, in particular:

- the development of a national housing advice and information service and investment in rapid response repairs and adaptations services (see 3.1, 3.5)
- continuing progress on improving access to public transport and the commitment to enhance the mobility opportunities of people for whom public transport is not likely to be the best way to meet their needs (section 4)

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- our commitment to promote personalisation of health and social care services (5.3, 7.1), and to increase the take-up of direct payments amongst currently under-represented groups (7.3). We will ensure that the same range of options and opportunities for independent living that exist for others, are also offered to older people; and will explore the efficacy of promoting choice and control for older people in residential/nursing care or at risk of entering residential/nursing care (see section 2).

Underpinning all of this is a need to disseminate an understanding of what independent living means for older disabled people so that this empowering approach is reflected in services aimed at meeting their needs. Our communication strategy (see section 1) will play a major role here. In addition, as set out below, we will produce a resource, in the form of a best practice toolkit, that covers both current policy and performance levers for change and examples of good practice in widening opportunities and options that further promote independent living for older disabled people.

9.1 Develop a cross-government toolkit to assist the development of local independent living strategies for older people

The ODI, in partnership with other government departments, will develop and publish a cross-government toolkit that provides a 'one stop' information resource on independent living for older people at a national, regional and local level. This resource will highlight the drivers for implementing independent living with and for older people in existing policy and legislation, including examples of best practice across all aspects of public service commissioning and delivery (housing, transport, health and social care, education, employment, volunteering and so on). Clear references will also be made to the range of practical guidance that currently exists, or is in development, across different policy arenas, as well as addressing gaps identified in an initial scoping phase of work. Above all, this resource will set out the key components of independent living and its relevance and application to older people in one place, including effective mechanisms for the involvement of older disabled people in the development of local and national strategies.

Five years from now:

This will be different...

Older disabled people will be directly involved in the development and implementation of policies, strategies and plans at national, regional and local levels.

Older people with support needs will be accessing the same range of options and opportunities for independent living as younger disabled people.

We will know this because...

Older people's involvement will be evident across a range of policies, services and initiatives.

There will be an increased take-up of direct payments by older people, an increase in the numbers of older disabled people assisted to live in their own homes and a percentage reduction in those, (including self-funders), who move into residential care. Significant progress will have been made in enabling older people to access and use an individual budget.

Note: Details of how progress will be measured are given in **Annex C**.

10. Young disabled people in transition to adulthood

Rationale and intended outcomes

Transition planning and service provision is not working for many young disabled people. Transition to adulthood is not just about leaving school but takes place over a longer period and involves many more aspects of a young person's life.



16 to 17 year old young disabled people are twice as likely, and 18 to 19 year old disabled people three times as likely, as young non-disabled people, to be not in education, employment or training²². By the age of 26 young disabled people are nearly four times as likely to be unemployed or economically inactive, as young non-disabled people. Young disabled people have very limited opportunities for moving away from the parental home and these are more often determined by service availability and eligibility criteria, than by young people's choices about where to live and who to live with. The take-up of direct payments amongst young people remains low. Some groups of young disabled people are at a disproportionate risk of disengaging with health services, with consequently poorer health outcomes.

Over the course of the five year Strategy, we would expect to see improvements in the percentages of young disabled people who have transition plans and who have access to person centred planning and advocacy services. Progress will also be measured against the targets for reducing the numbers of young people who are not in education, employment or training, and in young disabled people's housing and other opportunities.

22 Youth Cohort Study, Parliamentary Briefing, Disability Rights Commission, 2007.

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Ruth is 15 and needs equipment to enable her to get around, communication assistance, and personal assistance with all her physical needs (which include needs relating to her health). She also has learning disabilities. In the next few years, Ruth wants to get qualifications, and then a job and/or to engage in other meaningful activity. She also wants to start living away from her family, spend time with her friends, and make new friends and relationships.

An effective independent living strategy will mean that Ruth has choice and control over how her needs for assistance and/or equipment are met and there is continuity in how these needs are met and funded. It will mean that she has access to personal assistance when she needs it, delivered in a way which enables her to do the things she wants to do. This will include not just help with things like getting up and getting dressed, but also help with regular stretching of her limbs and regular intra-tracheal suction. It will mean she has the equipment needed to enable her to communicate, people to understand how she communicates, and access to equipment and transport to enable her to move around. She would also have access to housing which is suitable to her needs; education and training opportunities relating to her ability and interests; opportunities for holidays, leisure activities, hobbies, and volunteering according to her interests and inclination; and equality of opportunity to take on a job for which she is qualified and suited.

Commitments

10.1 Transition between children's and adults' services

The Government's objective is to improve the transition between the ages of 14 to 25 and to make progress on the commitment in 'Improving the Life Chances of Disabled People'²³ to remove the 'cliff edge' between children's and adults' services. The overarching ambition is to ensure a seamless transition into adulthood for young disabled people, including those with complex health needs, in all aspects of their life, including between children's and adults' services, as well as in employment, education and training, transport and housing. This support should continue throughout the transition period and include young disabled people up to, and beyond, the age of 19.

23 Prime Minister's Strategy Unit, Cabinet Office, (2005), 'Improving the Life Chances of Disabled People'.

10.2 Transition Support Programme

A first step in reaching this objective will be to deliver a Transition Support Programme (14-19) as proposed in 'Aiming high for disabled children: better support for families'²⁴. This programme, led by the DCSF (formerly part of the DfES) and DH, will include:

- access to an advisor or key worker, advocacy and support, and person centred planning approaches from the age of 14
- joint team working across agencies and with adult services to encourage integrated assessments
- a holistic approach.

The programme will work with local authorities, PCTs and other local agencies to address a range of issues which can make the transition from childhood to adulthood particularly difficult for disabled children and young people.

The Transition Support Programme will start in April 2008, and the Government will work with stakeholders in advance of this to work up details building on the principles of the Early Support Model.

In the longer-term the Government will look to learn from, and build on, the 14 to 19 Transition Support Programme and identify aspects of services to improve practice to support the transition from childhood to adulthood between the ages of 14 to 25; (for example, the divide between children's and adults' services, the transition from schools to post-16 provision and employment, and promoting choice, control and independent living).

A number of initiatives are already underway to support young disabled people to move successfully from childhood to adulthood (see 10.3 to 10.8).

24 Department for Education and Skills, Her Majesty's Treasury, (2007), 'Aiming high for disabled children: better support for families'.



10.3 Delivering the cross-government strategy for post-16 learners with learning difficulties/disabilities

Progression through Partnership is a cross-government strategy for post-16 learners with learning difficulties/disabilities which aims to create more sustainable and seamless services, and highlights the particular barriers faced by young people with learning disabilities. The Getting a Life Demonstration Project aims to address the issues faced by young people with a learning disability as they move from compulsory education into adult life. This pilot will involve local employment, education and day services functions working together in an integrated manner. This will help, through joint models of planning, working and funding, enable young people going through transition to have greater control and choice in terms of how they move from school to college or further training and then into work. DCSF, DH, Department for Innovation, Universities and Skills (DIUS) and DWP are all linked into the project. The evaluation of Getting a Life work, together with the Transition Support Programme, should provide useful evidence of how services can work together to support a young disabled person across the whole spectrum of transition needs.

10.4 Public consultation on specialist disability employment programmes for disabled people who have complex barriers to entering and retaining employment

As set out in commitment 6.1, the DWP is undertaking a public consultation on proposals to improve their specialist disability employment programmes for disabled people who have complex barriers to entering and retaining employment. This consultation which was published on 3rd December 2007, proposes ways in which our current WORKSTEP, Work Preparation and Job Introduction Scheme, can be improved to provide a more seamless service, with a better focus on the needs of individual customers, including supporting people when they are moving from education and into work.

10.5 Reduce the proportion of young people aged 16 to 18 who are not in education, employment or training

The Government is committed to reducing the proportion of young people, aged 16 to 18 who are not in education, employment or training and DCSF has a target to reduce the proportion of 16 to 18 year olds who are not in education, employment or training by two percentage points by 2010. The DWP, Jobcentre Plus and DCSF are working together to ensure that Connexions Services are successfully transferred to local authorities, and that they will provide effective services to young people from April 2008 to ensure appropriate provision that meets their needs and aspirations is available.

10.6 Supporting young disabled people to become independent users of transport

As set out in section 4, the Government is working to support disabled people, including young disabled people, to become independent users of transport, by: developing and delivering a strategy for providing information and confidence training for disabled people, so that they are enabled to access and use public transport; and, developing evidence-based strategies for enhancing the personal mobility options and range of modal transport choices for disabled people. This will include taking forward the findings from evaluation of the Disability Rights Commission's (DRC) GOJO campaign (see section 3).

10.7 Meeting the housing needs of young disabled people

CLG and DCSF have commissioned research to develop best practice guidance for local housing authorities and children's services on how they should work together to prevent homelessness, and assess and meet the needs of homeless young people. This will include ensuring young people have access to Children's and Adolescent' Mental Health Services and Adults' Mental Health Services, so that a co-ordinated response can be developed to meet the needs of young people with mental health issues at risk of homelessness.

CLG is working in partnership with the Young Men's Christian Association (YMCA) England and Centrepont to deliver the National Youth Homeless scheme. This includes a good practice knowledge base, which is hosted on a dedicated website launched in October 2007. The knowledge base includes case studies and practical tools on tackling and preventing youth homelessness, including working in partnership and providing service specifications for services to support young people with wider health and complex needs. The good practice is being disseminated through ten Regional Centres of Excellence on youth homelessness, national conferences, and a specialist adviser, who works with local authorities to improve their range of interventions and services, to prevent and tackle youth homelessness.

10.8 Support young people to become active members of their local community

The Young Advisors Scheme, funded by the CLG, will:

- support local authorities and all public sector host agencies to engage young disabled people as Young Advisors, by building on existing guidance and supporting materials, and developing and disseminating best practice case studies
- ensure that Young Advisors are aware that meeting the needs of young disabled people in the local community will also be an important aspect of their work, by incorporating information and guidance on disability issues into the Young Advisor training
- commission its development manager to explore how the Young Advisors Scheme can assist local authorities in recruiting more young disabled people.

10.9 Individual budgets for disabled children and young people

Given the potential benefits in terms of flexibility and choice, 'Improving the Life Chances of Disabled People'²⁵ recommended that individual budgets should in principle be extended to families with disabled children. In 'Aiming high for disabled children: better support for families'²⁶ the Government

25 Prime Minister's Strategy Unit, Cabinet Office, (2005), 'Improving the Life Chances of Disabled People'.

26 Department for Education & Skills, Her Majesty's Treasury, (2007), 'Aiming high for disabled children: better support for families'.

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made a commitment to examine this potential in greater depth. The DCSF will commission a scoping study to examine different approaches to testing out individual budgets for disabled children and young people. Subject to the outcomes of the study, the Government will pilot individual budgets for disabled children and young people, building on the current scoping exercise, with full evaluation by 2011.

Five years from now:

This will be different...

Young disabled people will have choice and control over the support they need and will receive any necessary assistance required to achieve choice and control, such as person centred planning, advice and information, and advocacy support.

Young disabled people will have increased employment, housing and volunteering opportunities.

Young disabled people will experience continuity in the meeting of their health care needs and have increasing choice and control over how non-acute health care needs are met.

We will know this because...

More young disabled people will have person centred plans, a smooth transition process to adulthood, direct payments and individual budgets.

Young disabled people will have similar opportunities for cultural, sporting and leisure activities as their non-disabled peers.

There will be a reduction in the number of young disabled people not in education, employment or training, an increase in volunteering and in the percentage of young disabled people living in their own homes.

Young disabled people will express greater satisfaction with how their health care needs are met.

Note: Details of how progress will be measured are given in **Annex C**.

11. Disabled parents

Rationale and intended outcomes

About 12% (1.7 million) of Britain's 14.1 million parents are likely to meet the Disability Discrimination Act definition of a disabled person and 1.1 million households with dependent children have at least one disabled parent.²⁷ Not all disabled parents require additional support but those that do often fall between children's and adults' health and social services. Disabled parents, (and specifically parents with learning disabilities and parents with mental health support needs), were identified by both Her Majesty's Treasury (HMT)/ Department for Education and Skills' (DfES) Children and Young People Review, Social Exclusion Task Force, as families who would particularly benefit from more joined-up working across children's and adults' health, education and social care. There is also evidence that mainstream health, education and parenting support services sometimes have difficulty responding to the needs of families affected by parental disability. Disabled parents and their families face a higher risk of poverty. Thirty three per cent of all children living in households with one or more disabled adult and no disabled child are at risk of poverty, whilst 24 per cent of children in households with one or more disabled adult and one or more disabled children are at risk compared to 20 per cent for those with no disabled person present.²⁸

Our policies aim to promote more joined-up working between health, education and social care to provide timely and flexible support where this is needed, and to encourage policies and services aimed at parents in general to include families affected by parental disability.

There are currently no indicators which would enable measurement of improvements in support to disabled parents. We are continuing to explore possibilities, and our first commitment set out below aims to identify outcome measures for the impact of protocols for joint working. General socio-economic disadvantage can be measured using the Labour Force Survey and Family and Children's Study.

27 SCIE Knowledge Review No 11, <http://www.scie.org.uk/publications/knowledgereviews/kr11.asp>

28 Households Below Average Income Series 2005/06 (Revised), ONS, 2007

Rhona is 28 years old and has learning disabilities. She has two children, Tommy aged eight and Laura who is four months old. She lives with her partner Alex. Rhona received a lot of support from her mother during the early years of her first child's life but her mother has now moved out of the area. Rhona has had difficulty engaging with health and education services as she feels they do not understand her needs for accessible information. The health visiting service feels she is disengaging from them and are having difficulty monitoring the baby's progress. Tommy's school is concerned as he has started to have unexplained absences. Alex says that he, Rhona and Tommy have been verbally abused by young people in their street and this is causing them a lot of distress.

An effective independent living strategy will:

- enable Rhona to get the support she needs at an early enough stage to enable her to care for her children
- mean that maternity, health and education services are fully accessible, in particular in terms of their communication methods and their attitudes
- mean that flexible and practical parenting support is available for as long as she needs it, and at the specific points when needed in her family's life cycle
- mean that she and her partner receive help with other issues such as housing, harassment, employment, debt and benefits advice.

Commitments

11.1 Promoting good practice in children's and adults' health, education and social care

11.1.1 The SCIE will disseminate the Resource Guide on supporting disabled parents by, in the first instance, working with a region to demonstrate how to develop inter-agency protocols to support disabled parents and their children²⁹. This project will aim to measure the impact of inter-agency protocols on outcomes for parents and children and work with the CSCI to explore the implications for inspection and performance assessment.

29 Resource Guide is available on the SCIE website: <http://www.scie.org.uk>

11.1.2 In ‘Aiming high for children: supporting families’³⁰, the Government announced that £13million will be provided over the next three years to ‘enable a significant number of local areas to set up pathfinders delivering intensive and tailored family support’. The pathfinders will pilot the following mechanisms:

- multi-agency teams and/or dedicated professionals, backed up by strategic level commitment of relevant agencies
- support tailored and personalised according to individual families’ needs
- front-line staff working assertively to engage with families
- involving service users in the development and delivery of support services.

Families affected by parental mental health problems or learning disabilities are expected to be part of the target groups. The programme will work with key stakeholders for target groups, for example, the Parental Mental Health And Child Welfare Network and Working Together with Parents with Learning Disabilities Network.

11.2 **Involving disabled parents in all activities relating to supporting families**

11.2.1 All information produced by government departments, aimed at parents, will be made available in accessible formats.

11.2.2 The Families Unit in DCSF will be running a Parenting Implementation Project to help local authorities develop a more strategic and joined-up approach to parenting support and to strengthen the use of evidence-based parenting interventions through extended schools’ and children’s centres.

Disabled parents will be one of the focus areas for this Project.

30 Department for Education & Skills, Her Majesty’s Treasury, (2007), ‘Aiming high for children: supporting families’.

11.3 Child poverty and parental disability

The Child Poverty PSA Delivery Agreement recognises that children living in families where one or both parents are disabled, are at risk of living in poverty. Disabled parents are one of the priority groups for supporting parents into work. ODI will work across Government to help the policies which tackle child poverty and unemployment address the needs and circumstances of families affected by parental disability.

Five years from now:

This will be different...

Children’s and adults’ health, education and social care services will be working together to provide personalised support to families affected by parental disability/ill health.

Disabled parents will have equal access to information and parenting support.

There will be an improvement in access to child care amongst families affected by parental disability.

We will know this because...

Inspections of children’s and adults’ services will indicate a steady improvement in joint working across children’s and adults’ health, education and social care to support families. This will be reflected in feedback from parents and organisations representing them.

Information and parenting support will be available, in appropriate forms and formats, to parents with learning disabilities, parents with mental health support needs, and parents with physical and/or sensory impairments.

There will be an increase in the percentage of disabled parents using childcare (currently 46 per cent compared with 57 per cent of families where no-one is disabled).³¹

Note: Details of how progress will be measured are given in **Annex C**.



3. Measuring progress

Chapter 3 – Measuring progress

Introduction

1. Measuring progress on the aims and outcomes that the Government wishes to achieve will be an essential part of the delivery of the Independent Living Strategy. We have given some indication in the previous chapter of what difference the Strategy is intended to make to disabled people. Progress on achieving the Strategy's intended outcomes will be monitored annually and we summarise below how this will be done. **Annex C** sets out the detail of the links between how we will measure progress against the specific commitments listed in this report and the frameworks we will use to measure progress.

Monitoring progress

2. There are three frameworks which will be utilised to monitor and measure progress:
 - Public Service Agreements (PSAs) and Departmental Strategic Objectives (DSOs)
 - Performance framework for local authorities (national indicators)
 - Office for Disability Issues Outcome Indicators for measuring progress towards the 2025 vision of equal citizenship for disabled people³².
3. The key measures at a national level are the PSAs which set out the key improvements the public can expect from Government spending. These PSAs cover the period from 2008 to 2011. The PSA which is most relevant to independent living is:
 - PSA 15: 'Addressing the disadvantages that individuals experience because of their gender, race, disability, age, sexual orientation, religion or belief'.

In particular, progress against this target will be measured on the extent to which the Government closes gaps in independence and choice.

32 <http://www.officefordisability.gov.uk/consultations>

Chapter 3 – Measuring progress

Other PSAs which will also help measure progress toward independent living are:

- PSA 8: Maximise employment opportunity for all
 - PSA 14: Increase the number of children and young people on the path to success
 - PSA16: Increase the proportion of socially excluded adults in settled accommodation and employment, education or training
 - PSA 17: Tackle poverty and promote greater independence and well-being in later life
 - PSA 18: Promote better health and well-being for all
 - PSA 19: Ensure better care for all.
4. The new performance framework for local authorities and local authority partnerships will be underpinned by a single set of 198 outcome based national indicators. As set out in the ‘New Performance Framework for Local Authorities and Local Authority Partnerships: Single Set of National Indicators’³³, performance against each of the 198 indicators will be reported for every single tier and county council local strategic partnership (LSP). **Annex C** includes the national indicators relevant to particular outcomes for our Independent Living Strategy, which will be used to monitor progress, subject to finalising the technical definitions of the National Indicators.
5. There is, however, additional data that will be required to measure progress on some parts of the Strategy. In some cases, this additional data could be provided by secondary analysis of existing data sets, in others, the ODI’s forthcoming longitudinal survey may provide the information required, and some primary research may be needed. **Annex C** identifies some of the gaps in the information. The need for further research and analysis will be considered during the course of monitoring progress on the five year Strategy. We will work with the Government Equalities Office, the Office for

33 Communities and Local Government, (2007), ‘New Performance Framework for Local Authorities and Local Authority Partnerships: Single Set of National Indicators’.

National Statistics (ONS) and partners across Government, to take forward recommendations from the Equalities Data Review. We will aim to improve the evidence-base for equalities groups, and agree with key partners how best to capture information on the gaps, including through dis-aggregation of data at a local level where possible.

6. In addition, there is a need for more information on the experiences of specific groups of disabled people (for example, where we need to measure progress for BME disabled people). The ODI is committed to working with the Government Equalities Office to improve the availability of data in order to measure the experiences of disabled people according to their gender, age, ethnicity, religion and sexual orientation.

Legislation

7. The Independent Living Review was asked to consider whether legislative change is needed to address the barriers to independent living.
8. The Expert Panel, whilst broadly in agreement with the prioritised proposals, has expressed very strong concerns that the five year Strategy will have a limited impact and fail to meet the aspirations of disabled people without a legislative framework which, as a minimum, builds independent living principles into the language of social care legislation, and which provides for individual redress. Ideally, they would want a framework which guarantees a minimum standard of support.
9. The Government is committed to delivering improvements in independent living. The Equalities PSA 15 includes a focus on tackling barriers caused by gender, disability or age that limit people's ability to have choice and control over their lives. The new PSA underlines the high priority the Government attaches to improving choice and control for disabled people, including older disabled people. The new performance framework will incentivise improvements in local delivery and provide a robust mechanism for monitoring and challenging progress.

Chapter 3 – Measuring progress

10. In terms of redress, the Government's new approach to complaints about health and social care will make the experience of making a complaint easier, more user-friendly, co-operative and much more responsive to people's needs. As set out in 'Making Experiences Count: a new approach to responding to complaints'³⁴ there will also be a statutory right to independent advocacy, as is already available to people making health complaints via the Independent Complaints Advocacy Service (ICAS).
11. The Health and Social Care Bill presented to Parliament in November 2007 addresses some concerns about the legislative framework. It makes provision for direct payments for people who are currently excluded, removes the power of a local authority to ask a husband or wife to contribute towards the cost of residential care for their spouse, and clarifies the 'ordinary residence' rule.
12. The Government acknowledges the Expert Panel's views on legislation. However, the Government considers that there should be no change to primary legislation unless the current legislative framework poses insurmountable barriers to implementing current policy, and that such barriers have not yet been identified. The current focus on personalisation and the individual budgets pilots do not require any substantive change to legislation. We will, however, review the need for legislation if the performance framework does not deliver sufficient progress against the outcomes of the Strategy.

Commitments

- 12.1 The ODI will report on progress on the Independent Living Strategy, as part of the ODI annual reporting process
- 12.2 Life Chances departments will review, in time for the next Spending Review and performance framework, whether further action to deliver outcomes is needed
- 12.3 The Government will review the need for legislation if sufficient progress has not been made against the outcomes by 2013.

34 Department of Health, (2007), 'Making Experiences Count: a new approach to responding to complaints'.



4. Consultation on implementation of the Independent Living Strategy

Chapter 4 – Consultation on implementation of the Strategy and the involvement of disabled people

1. One of the clearest messages from disabled people during the course of the Independent Living Review has been that there is a significant gap between national policy aims and local implementation. In other words, the lived experiences of disabled people, (including older disabled people), are too often too far removed from the Government's vision and policy aims.
2. At the same time, disabled people have told us that they should be involved in both the development and the implementation of policies which affect, their lives and services, and aim to meet their needs. The Expert Panel emphasised that there needs to be capacity building amongst disabled people of all ages, to enable them to play a leadership role, at national and local levels, to promote independent living. The Expert Panel also considered a range of different mechanisms to support delivery.
3. The Government recognises the importance of moving beyond consultation to co-production. Disabled people have been involved in the development of our five year Strategy. It is equally important that they are involved in implementing and monitoring progress on the Strategy. Therefore, the Government is consulting formally on implementing the Independent Living Strategy and on involving disabled people in this. Full details of the consultation and a summary of the consultation questions are in **Annex D**.
4. We would welcome views on the best arrangements to:
 - take a cross-government approach to scrutinizing the implementation of the five year Strategy
 - involve disabled people and their organisations, (including older disabled people), in implementing and monitoring progress on the Strategy
 - support delivery of the Strategy.

Proposals

Oversight of implementation of the Independent Living Strategy

5. The Office for Disability Issues (ODI), ODI Board of Management and Life Chances Ministerial Group should:
 - continue to champion a cross-government approach to independent living for disabled people
 - work with the Government Equalities Office to deliver independent living across the equalities strands
 - have a co-ordinating and oversight role to monitor progress, including progress on the involvement of disabled people and their organisations, in the implementation and monitoring of the Strategy.
6. The departments with lead responsibility for specific parts of the Strategy should monitor and report progress to the ODI Board of Management and Life Chances Ministerial Group (within any revised cross-government programme management structure), using the outcomes framework set out in **Annex C**.
7. In order to promote a cross-government approach to the delivery of the different policy areas covered in the Independent Living Strategy, ODI Board members should sponsor regular updates to the ODI Board of Management on the themes which most relate to their area of responsibility (for example, the Department for Work and Pensions (DWP) and employment), taking responsibility for updating on activity across Government relevant to each theme, and using the outcomes framework set out in **Annex C**.
8. It is expected, and welcomed, that Equality 2025 will continue to seek and communicate the views of disabled people on independent living and feed these through to the ODI Board of Management and Life Chances Ministerial Group.
9. ODI and Life Chances departments should review governance arrangements in year three (2010-11), if sufficient progress, as measured using the outcomes framework set out in **Annex C**, is not being made towards delivering independent living.

10. In addition to the arrangements set out in paragraphs five to eight, we would welcome views on setting up an Independent Living Scrutiny Group to monitor and scrutinise progress on the Strategy on an annual basis and report to the ODI Board of Management and Life Chances Ministerial Group. Membership would include members of Equality 2025 and additional members drawn from the Expert Panel which advised the Independent Living Review.

Consultation question 1:

We would welcome views on how best to involve disabled people, at a national level, in the monitoring of progress on implementation of the Independent Living Strategy, for example, by setting up an Independent Living Scrutiny Group.

Existing arrangements to encourage involvement of disabled people

11. The new local government performance framework and Comprehensive Area Assessments (CAA), which come into effect in April 2009, will encourage involvement of disabled people in the commissioning and monitoring of local services.
12. The Disability Equality Duty (DED) requires public bodies to involve disabled people in the development of their disability equality schemes and the Code of Practice encourages the ongoing engagement of disabled people as schemes are implemented.
13. 'Improving the Life Chances of Disabled People' acknowledged that local organisations, run and controlled by disabled people 'would be a vital part of the implementation of a new approach to supporting independent living'; the Department of Health (DH) is currently leading work to take forward the report's recommendation 4.3 in 'Improving the Life Chances of Disabled people' that 'by 2010, each locality.... should have a user-led organisation modelled on existing CILs' (Centres for Independent Living).³⁵ Such organisations could provide the local focal point for the engagement of disabled people in the implementation of the Strategy.

35 Prime Minister's Strategy Unit, Cabinet Office, (2005), 'Improving the Life Chances of Disabled People'.

Chapter 4 – Consultation on implementation of the Strategy and the involvement of disabled people

14. ‘Aiming high for disabled children: better support for families’³⁶ makes a commitment to improve the way in which parents, young people and children work with those responsible for services – so they can say what services are needed and how they should be delivered. We want to do this through improving participation locally – including by using parent forums – but we need to make sure that those responsible for services also capture the views of children and young people.
15. Other initiatives, such as Local Involvement Networks (LINKs), aim to promote local people’s involvement in shaping the services they use.

Consultation question 2:

We would welcome views on current arrangements for promoting the involvement of disabled people and their organisations and the contribution these arrangements may make to the monitoring of the Independent Living Strategy.

16. There are many existing networks of disabled people which, if they could be drawn together, could provide a substantial resource for the involvement of disabled people in the implementation and monitoring of the Independent Living Strategy at local and regional levels. Some work has commenced within the ODI to identify relevant existing networks, while at the same time making links with current initiatives such as the DH’s project on user-led organisations and LINKs.

Consultation question 3:

Is there a need for a “network of networks” to facilitate the involvement of disabled people in the implementation and monitoring of the Strategy?

36 Department for Education & Skills, Her Majesty’s Treasury, (2007), ‘Aiming high for disabled children: better support for families’.

Developing leadership capacity amongst disabled people

17. Our Expert Panel advised us of the importance of building capacity amongst disabled people of all ages to enable them to play a leadership role at national and local levels, to promote independent living and to be involved in implementation of the Strategy. The Panel were of the view that Partners in Policymaking™ is a useful model that could be adapted to promote disabled people's involvement in promoting the Independent Living Strategy.

Partners in Policymaking™ is a leadership training course for disabled adults and parents of disabled children. Building on an idea which originated in the United States, the first Partners in Policymaking™ course in Britain was held in Oldham in 1996.

Partners in Policymaking™ shows people how to ask the right questions, and how to present their questions to people who work in services without getting angry and frustrated. Everyone on the course becomes part of a network, so that they don't need to go to meetings or plan alone.....We make the Course as accessible as possible, we teach in lots of different ways....We work as a group supporting each other.... Graduates now form the base of a formal strong support network.³⁷

The Course covers lots of topics, encourages people to use microphones, shows them how to ask questions in the most productive way, practise making presentations, rehearsing how to get their point across, and working on assignments to give practical experience.

37 Text from the Partners in Policymaking™ website:
<http://www.partnersinpolicymaking.co.uk/index.php>

Consultation question 4:

We would welcome views on current initiatives to build leadership capacity amongst disabled people, on whether further work should adapt the Partners in Policymaking™ model, and/or whether there are other models we should consider.

Supporting implementation

18. The Expert Panel considered a paper on implementation written by its Vice Chair. This identified a range of different mechanisms to support delivery (with different cost implications). The functions of a supporting delivery mechanism are:
- the development of advice and good practice materials and support
 - peer support and shared learning opportunities (usually at a regional level)
 - leadership development and support
 - ‘critical friend’, challenging when initiatives are not in the spirit of policy intent
 - linking and networking people together from different places and sectors
 - facilitating the creation of an environment that makes it easier for local people to achieve change, for example, through developing stronger relationships and engaging with regionally organised delivery bodies.
19. Under the new performance framework the Government Offices for the Regions will provide the essential link between national and local government. There is a need for Government Offices for the Regions to maintain strong links with local strategic partnerships (LSPs) on independent living, linking with Regional Improvement and Efficiency Partnerships (which are made up of local authorities and involve other key

Chapter 4 – Consultation on implementation of the Strategy and the involvement of disabled people

partners in the region), and user-led organisations to spread good practice, and monitor the implementation of the Independent Living Strategy. As part of the communications strategy to raise awareness amongst practitioners and create a shared understanding of the principles of independent living, we will include targeted information and guidance for Government Offices for the Regions. We will also develop toolkits and guides on how to embed the principles and practices of independent living to support LSPs.

Consultation question 5:

We would welcome views on the best ways to assist implementation and monitoring of the Strategy at regional and local levels.

Consultation question 6:

We welcome any other views on the Independent Living Strategy.



Annexes and glossary

Annex A – How disabled people have been involved in the development of the Strategy

A life course approach embedded in the real life and diverse experiences of disabled people

1. The Independent Living Review has taken a case study approach to developing evidence-based policy commitments so that the Strategy is grounded in the lived experiences of disabled people. We have used some case studies to illustrate the outcomes that a successful Independent Living Strategy will achieve for disabled people. We also used quotes from disabled people who participated in the Review's work.
2. The Review has not covered young children, but has encompassed transition to adulthood (from the age of 14), through to very old age. The detailed commitments seek to address not only the barriers experienced by all disabled people, but also those faced by particular groups such as disabled people from black and minority ethnic (BME) communities, older people with high support needs, and young people with autistic spectrum disorder, (to name only three groups amongst many).

Involving disabled people – moving from consultation to co-production

3. A key starting point for the Review was that policies should be co-produced with the people whose lives they affect.

Disabled people should be involved at every stage.

The policies for independent living have to be led from the bottom up.

What makes things work is listening to disabled people's organisations and to disabled individuals.³⁸

38 Quotations in text boxes in Annex A are from disabled people who attended regional events or workshops held by the Independent Living Review.



4. We have therefore sought to develop our proposals by involving disabled people and other stakeholders. Together, we identified the barriers to independent living for particular groups and in specific circumstances. We also identified activities that would help address these barriers. We are consulting on our proposals but we have tried to move beyond consultation to co-production. Consultation happens once policy proposals have been developed; co-production means involving those who are affected by policy from the start. It means involving disabled people at all stages of policy development, implementation, and delivery.

If you want policies that work for people from BME communities you have to ASK people from those communities what would work for them and then LISTEN

5. We have used a variety of methods to involve disabled people and other stakeholders in the development of our policy proposals.

Expert Panel

6. Our Expert Panel, chaired by Baroness Jane Campbell, was set up to give expert advice to the Review. Members have contributed their direct experience as disabled people, family carers, as well as their experiences of commissioning, providing, regulating and inspecting local services. The nine meetings of the Expert Panel helped the Review team first, map and analyse existing policies, second, through the use of case studies, to identify the barriers and solutions to delivering independent living, and third, develop and prioritise our policy proposals. They have also provided important information on the issues relating to BME communities, and harder to reach groups, and considered the issue of legislation.
7. Details of Expert Panel membership and minutes of the meetings are published on the ODI website³⁹.

39 <http://www.officefordisability.gov.uk>

Annex A – How disabled people have been involved in the development of the Strategy

Workshops and events

8. We have also held workshops to bring together disabled people and other stakeholders to examine barriers, and solutions, in some particularly important policy areas:

- transition to adulthood for young disabled people
- older people and independent living
- support, advocacy and brokerage services.

In addition, groups of disabled people concerned with specific policy areas have helped us to develop our policy proposals relating to disabled parents, people with learning disabilities, people with mental health support needs, older people, and employment.

9. We held four regional events to help us to test out our emerging proposals with disabled people and other stakeholders. A summary of what disabled people told us at these and our other co-production events held during the course of the Review has been posted on our website.⁴⁰

10. The main messages from disabled people are:

- there is too big a gap between what national policy says should happen and disabled people's actual experiences
- disabled people should be closely involved in both the development and the implementation of policies which affect their lives
- when disabled people need support or equipment to go about their daily lives this should be delivered in ways which:
 - enable individuals to make decisions for themselves
 - do not fragment their lives across different budgets or services

40 <http://www.officefordisability.gov.uk>

Annex A – How disabled people have been involved in the development of the Strategy

- disabled people cannot achieve full and equal citizenship unless they have choice and control over the support needed to go about their daily lives, and equal access to housing, transport and mobility, health, employment and education opportunities.

Legislation is not implemented so it becomes 'lip service'.

It's time for DOING, not TALKING.

Government needs to stop talking about all of this and start doing it.

Making the links

11. We have linked up with Equality 2025 through their representation on our Expert Panel, and by the attendance of individual Equality 2025 members at our workshops and regional events.
12. The Independent Living Review team has contributed to other Government work which has involved talking to disabled people running concurrent to our review, including:
 - Her Majesty's Treasury (HMT)/DfES Children and Young People Review
 - Third Sector Action Plan
 - Families At Risk Review
 - Child Poverty Review
 - HMT Review of Intensive Support for Older People
 - DH User-led Organisations Project

Annex A – How disabled people have been involved in the development of the Strategy

- Supporting People Strategy
 - Mental Health and Employment Review
 - PSA frameworks: Later Life; Equalities; Social Exclusion
 - Opportunity Age
 - LinkAge Plus
 - Lifetime Homes; Lifetime Neighbourhoods Housing Strategy for an Ageing Society
 - Independent Living and Older People Forum.
13. These links have demonstrated the importance of a cross-government approach since the aim of delivering independent living for all disabled people cuts across a wide range of policy areas.

Annex B – Summary of commitments, timetable and lead departments

No.	Policy area	Lead dept	Timetable
1.	Communications		
1.1	Awareness building and attitude changing programme to create support for an independent living approach	ODI	2008-09
1.2	Communicate independent living messages to practitioners	ODI with cross-govt input	2008-09
1.3	Communication materials for practitioners	ODI lead	2009-10
1.4	Communicate independent living messages to users and potential users of services and carers	ODI lead with cross-govt input	2010-13
1.5	Focus on specific communication needs of different groups of disabled people, including black and minority ethnic (BME) communities and older people	ODI	2010-13
2.	Action and Learning Sites and Regional Initiatives		
2.1	Scoping work for two initiatives:		
	1. Action and Learning Sites to demonstrate redeployment of resources from professional assessment and care management to user-led support, advocacy and brokerage	ODI	2007-08

Annex B – Summary of commitments, timetable and lead departments

No.	Policy area	Lead dept	Timetable
	2. A regional initiative to demonstrate the efficacy of investing in independent living for older disabled people in residential/nursing care or at risk of moving into care	ODI	2007-08
2.2	Following on from scoping exercise, decisions will be made concerning the design of, and investment in, the Action and Learning Sites and Regional Initiative	ODI/DH	2008-11
3.	Housing		
3.1	Increase the provision of housing advice and information	CLG	2007-08
3.2	Update Lifetime Homes standard and the Code for Sustainable Homes	CLG	2008-13
3.3	Lifetime Homes standard and the private sector	CLG	2011-12
3.4	Accessible Housing Registers	CLG	2007-08
3.5	Investment to provide rapid response repairs and adaptations services	CLG	2008 and ongoing
3.6	Early Intervention	CLG	2008-09
3.7	Disabled Facilities Grant	CLG	2008
3.8	Supporting People	CLG	Ongoing
4.	Transport and Mobility		
4.1	Evidence-based strategies for enhancing personal mobility options and transport choices for disabled people	DfT	2008-09
4.2	Training of transport providers	DfT	2007-09
4.3	Information and confidence training for disabled people	DfT	2008-09 and ongoing

Annex B – Summary of commitments, timetable and lead departments

No.	Policy area	Lead dept	Timetable
4.4	Local transport plans and accessibility planning	DfT	2008-09
4.5	Stakeholder engagement including a specific focus on harder to reach groups	DfT	2008-13
5.	Health		
5.1	Education and awareness programme for NHS staff on increasing choice and control and Disability Equality Duty	DH	2008-09
5.2	Expert Patients Programme and self management – increasing take-up of existing programmes and developing new approaches that work for disabled people (including older people)	DH	2008-10
5.3	Choice and control and continuing health care	DH	2008-09
6.	Employment and economic wellbeing		
6.1	Action to improve specialist employment support services for disabled people	DWP	2007-09
6.2	Cross-government national strategy aimed at enabling people to remain in employment when they acquire an impairment or the condition worsens	DWP	2008-10
6.3	Increase access to volunteering opportunities for disabled people	OTS	2008-11
6.4	Participation in public and civic life	DWP/DH	2008-09
6.5	Investigation of impact of reforms to the benefit system, employment support programmes and charging policies within adult social care	ODI	2009-11

Annex B – Summary of commitments, timetable and lead departments

No.	Policy area	Lead dept	Timetable
6.6	Charging and residential care	DH/DWP	2009-10
6.7	The role of Disability Living Allowance (DLA) and Attendance Allowance (AA) in supporting independent living	DWP	2008-09
7.	Personalisation, choice and control		
7.1	Social care modernisation programme and individual budgets	DH/ODI	On-going
7.2	Work with In Control Total and ensure that this initiative is linked in with the five year Strategy	ODI	On-going
7.3	Continue to encourage and monitor take-up of direct payments by adults, particularly amongst currently under-represented groups	DH	On-going
8.	Support, information, advocacy and brokerage		
8.1	Support local organisations to develop local action plans for the mapping and provision of support, advocacy, information and brokerage services	CLG/DH	2007-09
8.2	Commission a scoping study to assess the need for, and the costs and benefits of providing, independent advocacy when disabled people are at risk of losing choice and control	ODI with cross-govt input	2008
8.2.1	Subject to the scoping study, commission research	ODI with cross-govt input	2008-11
8.3	User-led organisations	DH	2008-09
8.4	National Advocacy Qualification	DH	2009

Annex B – Summary of commitments, timetable and lead departments

No.	Policy area	Lead dept	Timetable
9.	Older disabled people		
9.1	Develop cross-government toolkit to assist development of local IL strategies for older people	ODI with cross-govt input	2008-11
	See section 2 Action and Learning Sites and Regional Initiatives		
10.	Young Disabled People in Transition to Adulthood		
10.1	Transition between children's and adults' services	DCSF/DH	2008/09 - 2010/11
10.2	The Transition Support Programme for 14-19 year olds as proposed by the HMT/DfES report 'Aiming High for Disabled Children' including children with complex health needs	DH/DCSF	2008/09 - 2010/11
10.3	Delivering the cross-government strategy for post 16 learners with learning difficulties/disabilities	DCSF/ DWP/DIUS/ DH	Four year programme, starting 2007
10.4	Public consultation on specialist disability employment programmes for disabled people who have complex barriers to entering and retaining employment	DWP	2007-08
10.5	Reduce the proportion of young people aged 16-18 who are not in education, employment or training	DCSF/DWP	2007-10
10.6	Support young disabled people to become independent users of transport	DfT	On-going
10.7	Meeting the housing needs of young disabled people	CLG/DCSF	2008-10

Annex B – Summary of commitments, timetable and lead departments

No.	Policy area	Lead dept	Timetable
10.8	Support young people to become active members of their local community	CLG	2007-09
10.9	Scoping study on individual budgets for disabled children and young people	DCSF	2007-11
11.	Disabled parents		
11.1	Promoting good practice in children's and adults' health, education and social care	See 11.1 and 11.1.2	See 11.1 and 11.1.2
11.1.1	Promote good practice: SCIE Resource Guide	DH/SCIE	2008-09
11.1.2	Promote good practice: Pathfinders	DCSF	2008-09
11.2	Involving disabled parents in all activities relating to supporting families	See 11.2.1 and 11.2.2	See 11.2.1 and 11.2.2
11.2.1	Accessible information for parents	DH/DCSF	2008-09
11.2.2	Parenting Implementation project	DCSF	
11.3	Work with government departments to help the policies to tackle child poverty and unemployment address the needs and circumstances of families affected by parental disability	DWP	On-going
12.	Monitoring and Legislation		
12.1	Report on the Independent Living Strategy as part of the ODI annual reporting process	ODI	Annually
12.2	Life Chances departments will review progress in time for the next Spending Review and performance framework whether further action to deliver outcomes is needed	Cross-govt	2009-10
12.3	Government will review the need for legislation if sufficient progress has not been made against the outcomes by 2013	DH/ODI	2012-13

Annex C – What difference will the Independent Living Strategy make to disabled people and how will we measure progress?

Annex C – What difference will the Independent Living Strategy make to disabled people and how will we measure progress?

This will be different because	We will know this because	How will it be measured: Relevant PSAs, indicators etc. Gaps in current data
Communicating independent living		
Government will have a co-ordinated and consistent approach to the promotion of independent living for all groups of disabled people.	A common understanding of what independent living means will be evident across Government and the Government Offices for the Regions in the context of housing, employment, education, transport, health and social care policies.	Review of policy documents would be required to assess consistency.

Annex C – What difference will the Independent Living Strategy make to disabled people and how will we measure progress?

<p>This will be different because</p>	<p>We will know this because</p>	<p>How will it be measured: Relevant PSAs, indicators etc. Gaps in current data</p>
<p>People working to commission and deliver local services used by disabled people, (including older disabled people), will have a better understanding of the meaning and importance of choice and control/self-directed support, and of commissioners' and practitioners' role in enabling independent living. They will have the tools that enable them to take this approach.</p>	<p>There will be an increase over time in the proportion of disabled people saying they have choice and control over the support needed to go about their daily lives.</p>	<p>Percentage of disabled people who say they have choice and control over the support needed to go about their daily lives. PSA 15; Omnibus Survey; ODI Life Chances Indicator.</p> <p>Percentages of disabled and older people saying they have been treated fairly by public services. PSA 15 NI 140.</p> <p>Additional data required to identify experiences of older and BME disabled people.</p>
<p>Housing</p>		
<p>Older people in any part of the country will be able to easily access housing advice and information.</p>	<p>Housing advice and information will be available in appropriate forms and formats, accessible to older disabled people.</p>	<p>Percentage of people over the age of 65 who say they receive the information, assistance and support needed to exercise choice and control. PSA 17 NI 139.</p> <p>Additional data required to identify experiences of older and BME disabled people.</p>

Annex C – What difference will the Independent Living Strategy make to disabled people and how will we measure progress?

This will be different because	We will know this because	How will it be measured: Relevant PSAs, indicators etc. Gaps in current data
<p>Disabled people will experience increased housing opportunities and will be more likely to live in housing which is suited to their needs.</p>	<p>There will be an increase in homes built to Lifetime Homes standard, the numbers of vulnerable people achieving independent living and in those supported to live independently by social services.</p> <p>There will be a decrease in the numbers of disabled people living in poor housing conditions and in housing which is not suitable to meet their needs.</p>	<p>Percentage of ‘vulnerable people’ achieving independent living. PSA 17 NI 141.</p> <p>People supported to live independently. PSA 18 NI 136.</p> <p>ODI Life Chances Indicator</p> <p>Satisfaction of people over 65 with both home and neighbourhood. PSA 17 NI 138.</p> <p>Additional data required to identify experiences of older and BME disabled people.</p>
<p>Transport</p>		
<p>Disabled people will have improved access to information and travel training, so they can make informed choices about using public transport and about alternatives when public transport is not suitable for them.</p>	<p>Information will be available from a range of sources and in accessible formats.</p>	<p>Review of information would be required.</p>

Annex C – What difference will the Independent Living Strategy make to disabled people and how will we measure progress?

This will be different because	We will know this because	How will it be measured: Relevant PSAs, indicators etc. Gaps in current data
<p>Disabled people will experience transport providers as being helpful and facilitating their access.</p>	<p>There will be an improvement in the percentage of disabled people who say that they have been treated fairly by services.</p>	<p>Percentages of disabled and older people saying they have been treated fairly by public services. PSA 15 NI 140.</p> <p>ODI Indicator: Experience of disability/health related difficulties in using public transport amongst disabled people.</p>
<p>It will be easier for disabled people to use public transport.</p>	<p>More disabled people will be using public transport.</p>	<p>Surveys (National Travel Survey, longitudinal survey) will show an increase in the numbers of disabled people using public transport.</p> <p>ODI Life Chances Indicator: Full size buses with low floor wheelchair access.</p>
<p>Health</p>		
<p>Disabled people will experience positive, enabling attitudes, behaviours and support from NHS staff in order to access the full range of health care information, advice, treatment and support that they need.</p>	<p>This will be evident from levels of complaints and from inspection activities.</p>	<p>Health Commission/EHRC reports.</p> <p>Percentages of disabled and older people saying they have been treated fairly by public services. PSA15 NI 140.</p>

Annex C – What difference will the Independent Living Strategy make to disabled people and how will we measure progress?

<p>This will be different because</p>	<p>We will know this because</p>	<p>How will it be measured: Relevant PSAs, indicators etc. Gaps in current data</p>
<p>Disabled people will have increased choice, control and flexibility over their non-acute and continuing health care.</p>	<p>Increasing numbers of disabled people will be reporting that they have choice and control over the support they need to live their everyday lives.</p>	<p>Percentage of disabled people who say they have choice and control over the support needed to go about their daily lives. PSA 15; Omnibus Survey.</p>
<p>Disabled people with specific conditions will be able to access information, advice and treatment options, including peer advice/support as well as support from trained professionals with specialist knowledge.</p>	<p>Examples of good practice illustrating what works, how and what makes it happen and support will be widely available for NHS staff and disabled people. A greater number and range of third sector organisations will be commissioned to provide information, advice, advocacy and self-care/management programmes.</p>	<p>End of life access to palliative care enabling people to choose to die at home. NI 129.</p> <p>People with long-term conditions supported to be independent and in control of their condition. NI 124.</p>
<p>Disabled people will have increased access to support to self-manage long-term conditions.</p>	<p>There will be increasing numbers of people with long-term conditions supported to be independent and in control of their condition.</p>	<p>Percentage of people over the age of 65 who say they receive the information, assistance and support needed to exercise choice and control. NI 139.</p> <p>Additional data required to measure progress for BME disabled people.</p>

Annex C – What difference will the Independent Living Strategy make to disabled people and how will we measure progress?

This will be different because	We will know this because	How will it be measured: Relevant PSAs, indicators etc. Gaps in current data
<p>Employment</p> <p>More disabled people will be helped into employment and employees who acquire an impairment, or whose existing impairment/condition worsens, will be more likely to remain in employment.</p>	<p>There will be a narrowing of the employment gap between disabled and non-disabled people.</p> <p>There will be fewer disabled people, and children of disabled parents, living in poverty.</p>	<p>People falling out of work and on to incapacity benefits. NI 173.</p> <p>ODI Life Chances Indicator: Employment rates for disabled and non-disabled people (by impairment).</p> <p>ODI Life Chances Indicator: Experience of unfair treatment/discrimination at work.</p> <p>Adults in contact with secondary mental health services in employment. PSA 16 NI 150.</p>
		<p>Adults with learning disabilities in employment. PSA 16 NI 149.</p> <p>Additional data required to measure progress for BME disabled people.</p> <p>ODI Life Chances Indicator: Percentage of children living in income poverty.</p> <p>ODI Life Chances Indicator: Individuals living in income poverty.</p>

Annex C – What difference will the Independent Living Strategy make to disabled people and how will we measure progress?

This will be different because	We will know this because	How will it be measured: Relevant PSAs, indicators etc. Gaps in current data
There will be an increase in access to volunteering opportunities for disabled people.	More disabled people will participate in volunteering activities.	ODI Life Chances Indicator: Volunteering among disabled people. (Citizenship Survey).
Disabled people will experience fewer disincentives to take public appointments.	There will be an increase in numbers of disabled people taking up public appointments.	ODI Life Chances Indicator: Civic participation of disabled people. (Citizenship survey) PSA 15 NI 3.
Personalisation, choice and control		
Disabled people will have greater choice and control over the support and/or equipment they need to go about their daily lives.	Support and equipment will be more personalised and fit better into people's lives.	Percentage of disabled people who say they have choice and control over the support needed to go about their daily lives. PSA 15; ONS Omnibus Survey. Self reported experience of social care users. PSA 19 NI 127. Numbers of 'vulnerable people' achieving independent living. PSA 17 NI 141. People supported to live independently. PSA 18 NI 136.

Annex C – What difference will the Independent Living Strategy make to disabled people and how will we measure progress?

This will be different because	We will know this because	How will it be measured: Relevant PSAs, indicators etc. Gaps in current data
	There will be an increased take-up of direct payments/ individual budgets across all service users' groups.	Monitoring of take-up of direct payments/groups of service users. DH DSO NI 130.
Individuals and their families (including self-funders) will have access to a range of high quality information and advice, advocacy and support brokerage.	There will be an increase in information and advice, advocacy and support brokerage services.	Percentage of people over the age of 65 who say they receive the information, assistance and support needed to exercise choice and control. PSA 17 NI 139. Measurement of progress on implementation of DH User-led Organisations project.
Responses to disabled people's needs will be more personalised.	People who need support in their daily lives will experience increased opportunities to participate in family and community life.	ODI Life Chances Indicator: Participation of disabled people in cultural, sporting and leisure activities. Additional data required to measure progress for BME disabled people. Social care clients receiving self-directed support (direct payments and individual budgets). DH DSO NI 130.

Annex C – What difference will the Independent Living Strategy make to disabled people and how will we measure progress?

This will be different because	We will know this because	How will it be measured: Relevant PSAs, indicators etc. Gaps in current data
Support, advocacy and brokerage		
Individuals and their families (including self-funders) will have access to a range of high quality information and advice, advocacy and support brokerage.	There will be an increase in information and advice, advocacy, support and brokerage services, including those provided by user-led organisations.	Percentage of people over the age of 65 who say they receive the information, assistance and support needed to exercise choice and control. NI 139. Measurement of progress on implementation of DH User-Led Organisations project.
Older people		
Older disabled people will be directly involved in the development and implementation of policies, strategies and plans at national, regional and local levels.	Older people's involvement will be evident across a range of policies, services and initiatives.	Examples of co-production with older people who need support to live their daily lives will be gathered through national and local evaluations of the POPP pilots. Older people's involvement will be evident from Comprehensive Area Assessments.

Annex C – What difference will the Independent Living Strategy make to disabled people and how will we measure progress?

<p>This will be different because</p> <p>Older people with support needs will be accessing the same range of options and opportunities for independent living as younger disabled people.</p>	<p>We will know this because</p> <p>There will be an increased take-up of direct payments by older people, an increase in the numbers of older disabled people assisted to live in their own homes and a percentage reduction in those, (including self-funders), who move into residential care. Significant progress will have been made in enabling older people to access and use an individual budget.</p>	<p>How will it be measured: Relevant PSAs, indicators etc. Gaps in current data</p> <p>Monitoring of take up of direct payments by older people. Percentage of people over the age of 65 who say they receive the information, assistance and support needed to exercise choice and control. PSA 17 NI 139. People supported to live independently through social services. PSA 18 NI 136.</p>
<p>Young disabled people in transition to adulthood</p>		
<p>Young disabled people will have choice and control over the support they need and will receive any necessary assistance required to achieve choice and control, such as person centred planning, advice and information, and advocacy support.</p>	<p>More young disabled people will have person centred plans, a smooth transition process to adulthood, direct payments, and individual budgets. Young disabled people will have similar opportunities for cultural, sporting and leisure activities as their non-disabled peers.</p>	<p>Evaluation of the Transition Support Programme. Young people's participation in positive activities. PSA 14 NI 110. Additional data required for young disabled people. ODI Life Chances Indicator: Participation of disabled people in cultural, sporting and leisure activities. Additional analysis required for young disabled people.</p>

Annex C – What difference will the Independent Living Strategy make to disabled people and how will we measure progress?

<p>This will be different because</p>	<p>We will know this because</p>	<p>How will it be measured: Relevant PSAs, indicators etc. Gaps in current data</p>
<p>Young disabled people will have increased employment, housing and volunteering opportunities.</p>	<p>There will be a reduction in the number of young disabled people not in education, employment or training, an increase in volunteering and in the percentage of young disabled people living in their own homes.</p>	<p>Proportion of 16-18 year olds who are not in education, training or employment. PSA 14 NI 117 – additional analysis/ data required to identify young disabled people. Additional data required to measure housing and volunteering experiences of young disabled people.</p>
<p>Young disabled people will experience continuity in the meeting of their health care needs and have increasing choice and control over how non-acute and continuing health care needs are met.</p>	<p>Young disabled people will express greater satisfaction with how their health care needs are met.</p>	<p>See measures under Health, which will need to be analysed according to age.</p>

Annex C – What difference will the Independent Living Strategy make to disabled people and how will we measure progress?

This will be different because	We will know this because	How will it be measured: Relevant PSAs, indicators etc. Gaps in current data
<p>Disabled parents</p> <p>Children's and adults' health, education and social care services will be working together to provide personalised support to families affected by parental disability/ill health.</p>	<p>Inspections of children's and adults' services will indicate a steady improvement in joint working across children's and adults' health, education and social care to support families. This will be reflected in feedback from parents and organisations representing them.</p>	<p>Comprehensive Area Assessments.</p> <p>Research may be required to gain feedback from parents.</p>
<p>Disabled parents will have equal access to information and parenting support.</p>	<p>Information and parenting support will be available, in appropriate forms and formats, to parents with learning disabilities, parents with mental health support needs, and parents with physical and/or sensory impairment.</p>	<p>Research and monitoring may be required of access to information and parenting support.</p>

Annex C – What difference will the Independent Living Strategy make to disabled people and how will we measure progress?

<p>This will be different because</p>	<p>We will know this because</p>	<p>How will it be measured: Relevant PSAs, indicators etc. Gaps in current data</p>
<p>There will be an improvement in access to child care amongst families affected by parental disability.</p>	<p>There will be an increase in the percentage of disabled parents using childcare (currently 46% compared with 57% of non-disabled parents).⁴¹</p>	<p>PSA 8: Maximise employment opportunity. ODI Life Chances Indicator on access to childcare (as measured by the Parents Childcare Survey). PSA 9: Child Poverty. PSA 15: Choice and control and flexibility.</p>

41 FACS 2006.

Annex D – Consultation on the Independent Living Strategy

Scope of consultation

- 1 This consultation applies to England only.

How can people respond to this consultation?

- 2 We want to ensure that we get views from as broad a range of people as possible about implementing the Independent Living Strategy and involving disabled people. As well as written responses to the questions we ask in this document, and any other points you would like to make, we will set up a number of other ways for people to tell us what they think. We will involve people through:
 - regional consultation events
 - local consultation events
 - responses submitted through the website.
- 3 Details of the consultation events we have planned, and copies of the consultation documents, can also be found in the consultations section of our website <http://www.dwp.gov.uk/consultations>

Annex D – Consultation on the Independent Living Strategy

- 4 This document is available in a range of formats, including Easy Read, Braille and audio, either from our website or on request from:

Name: Independent Living Strategy

Address: Office for Disability Issues
Department for Work and Pensions,
The Adelphi,
1–11 John Adam Street,
London WC2N 6HT

Phone: 0207 712 2845

Textphone: 0207 712 2032

Fax: 0207 962 8096

Email: Independent-living-review@dwp.gsi.gov.uk

- 5 The consultation period begins on 3rd March 2008 and runs until 20th June 2008. Please ensure your response reaches us by that date. Please send your consultation responses to the address above, or by email to Independent-living-review@dwp.gsi.gov.uk
- 6 When responding, please state whether you are doing so as an individual or representing the views of an organisation. If you are responding on behalf of a larger organisation, please make it clear who the organisation represents and where applicable, how the views of members were assembled. We will acknowledge your response.
- 7 We have sent this consultation document to a large number of people and organisations who have already been involved in this work or who have expressed an interest. Please do share this document with, or tell us about, anyone you think will want to be involved in this consultation.
- 8 The information you send us may be passed to colleagues within the Office for Disability Issues and Department for Work and Pensions and published in a summary of responses received, and referred to in the published consultation report.

- 9 All information contained in your response, including personal information, may be subject to publication or disclosure if requested under the Freedom of Information Act 2000. By providing personal information for the purpose of the public consultation exercise, it is understood that you consent to its disclosure and publication. If this is not the case, you should limit any personal information which is provided, or remove it completely. If you want the information in your response to the consultation to be kept confidential, you should explain why as part of your response, although we cannot guarantee to do this. We cannot guarantee confidentiality of electronic responses even if your IT system claims it automatically.
- 10 If you want to find out more about the general principles of Freedom of Information and how it is applied within DWP, please contact:

Name: Charles Cushing

Address: Department for Work and Pensions, Adjudication and Constitutional Issues, Information Policy Division, Freedom of Information Unit, 1-11 John Adam Street, London WC2N 6HT

Phone: 0207 962 8581

Email: charles.cushing@dwp.gsi.gov.uk or carol.smith14@dwp.gsi.gov.uk

More information about the Freedom of Information Act can be found on the website of the Ministry of Justice.

The consultation criteria

- 11 The consultation is being conducted in line with the Code of Practice on Consultation. The six consultation criteria are listed below, and the full version can be accessed at the Cabinet Office website.
- consult widely throughout the process, allowing a minimum of 12 weeks for written consultation at least once during the development of the policy
 - be clear about who may be affected, what questions are being asked, and the timescale for responses

Annex D – Consultation on the Independent Living Strategy

- ensure that your consultation is clear, concise and widely accessible
 - give feedback regarding the responses received and how the consultation process influenced the policy
 - monitor your department's effectiveness at consultation, including through the use of a designated consultation co-ordinator
 - ensure your consultation follows better regulation best practice, including carrying out a Regulatory Impact Assessment, if appropriate.
- 12 We value your feedback on how well we consult. If you have any comments on the process of this consultation (as opposed to the issues raised) please contact our consultation co-ordinator:
- Name:** Roger Pugh
- Address:** Department for Work and Pensions' Consultation Coordinator, Room 2A, Britannia House, 2 Ferensway, Hull HU2 8NF
- Phone:** 01482 609571
- Email:** roger.pugh@dwp.gsi.gov.uk
- 13 In particular, please tell us if you feel that the consultation does not satisfy these criteria. Please also make any suggestions as to how the process of consultation could be improved further.
- 14 If you have any requirements that we need to meet to enable you to comment, please let us know.

What will we do after the consultation?

- 15 The responses to the consultation will be published in the summer of 2008 in a report on our website that will summarise the responses and describe which areas are identified as being the most important. We will invite people who took part in the consultation to comment on this report when it is published.

Summary of consultation questions

Consultation question 1:

We would welcome views on how best to involve disabled people, at a national level, in the monitoring of progress on implementation of the Independent Living Strategy, for example, by setting up an Independent Living Scrutiny Group, as set out in Chapter 4, paragraph 10.

Consultation question 2:

We would welcome views on current arrangements for promoting the involvement of disabled people and their organisations and the contribution these arrangements may make to the monitoring of the Independent Living Strategy.

Consultation question 3:

Is there a need for a “network of networks” to facilitate the involvement of disabled people in the implementation and monitoring of the Strategy?

Consultation question 4:

We would welcome views on current initiatives to build leadership capacity amongst disabled people, on whether further work should adapt the Partners in Policymaking™ model, and/or whether there are other models we should consider.

Consultation question 5:

We would welcome views on the best ways to assist implementation and monitoring of the Strategy at regional and local levels.

Consultation question 6:

We would welcome any other views on the Independent Living Strategy.

Glossary

AA	Attendance Allowance
BME	black and minority ethnic
CAA	Comprehensive Area Assessment
CIL	Centre for Independent Living
CLG	Communities and Local Government
CRAG	Charging for Residential Accommodation Guide
CSCI	Commission for Social Care Inspection
CSIP	Care Services Improvement Partnerships
DCSF	Department for Children, Schools and Families
DDA	Disability Discrimination Act
DED	Disability Equality Duty
DfES	Department for Education and Skills
DFG	Disabled Facilities Grant
DfT	Department for Transport
DH	Department of Health
DIUS	Department for Innovation, University and Skills
DLA	Disability Living Allowance
DRC	Disability Rights Commission
DSO	Departmental Strategic Objective
DWP	Department for Work and Pensions
EHRC	Equality and Human Rights Commission
ESA	Employment Support Allowance

Glossary

GP	General Practitioner
HMT	Her Majesty's Treasury
ICAS	Independent Complaints Advocacy Service
LINKs	Local Involvement Networks
LSP	Local Strategic Partnership
NHS	National Health Service
NI	National Indicators
NROSH	National Register of Social Housing
ODI	Office for Disability Issues
ONS	Office for National Statistics
OTS	Office of the Third Sector
PCTs	Primary Care Trusts
POPP	Partnerships for Older People Project
PSA	Public Service Agreement
SCIE	Social Care Institute for Excellence
YMCA	Young Men's Christian Association

Credits:

Image of lady and child on front cover and page 7 posed by models,
courtesy of www.johnbirdsall.co.uk

Image of older lady on front cover and page 33,
courtesy of www.johnbirdsall.co.uk

This report is also available in audio, Braille and Easy Read formats. If you would like a copy in any of these formats, please contact the Office for Disability Issues:

**Address: Office for Disability Issues, 6th Floor, The Adelphi,
1–11 John Adam Street, London, WC2N 6HT**

Email: office-for-disability-issues@dwp.gsi.gov.uk

Telephone: 020 7962 8799

Textphone: 020 7712 2032

You can also download this report from the ODI website at www.officefordisability.gov.uk in PDF, RTF, audio and Easy Read formats.

We would welcome feedback on this report. Please use the contact details above if you wish to do so.

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