



**Independent Living Strategy  
Consultation Toolkit  
Support Material**

**3 March – 20 June 2008**

Following is some background information to support you in responding to the consultation. This includes:

- Independent Living executive summary
- Two-page summary of the Independent Living Strategy
- What is Independent Living?
- Independent Living case studies
- Key links

If you are accessing this pack from our website:

- the executive summary can be downloaded from this address <http://www.officefordisability.gov.uk/working/independentlivingstrategy.asp - summary>
- there is a DVD of case studies available if you contact us directly and
- copies of an independent living supplement which appeared in The Times and an article about the strategy which appeared in Guardian Society can be posted to you if you contact us directly. Contact details are given on page 11 of the consultation toolkit document.

# The Independent Living Strategy

The aims of the Government's five year Independent Living Strategy are 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 and
- disabled people, (including older disabled people), will have greater access to housing, health, education, employment, leisure and transport opportunities and to participation in family and community life.

The strategy includes the following commitments to:

- **communicate the principles and practice of independent living**, both to practitioners and disabled people, with a particular focus on harder to reach groups
- **develop initiatives to demonstrate** the case for investment in independent living, with a focus on older people with high levels of support needs, and on support, advocacy and brokerage services provided by user-led organisations
- increase disabled people's housing opportunities and choices
- build on progress made on making public transport accessible and seek to improve options for people whose needs cannot be met by public transport
- design and deliver an **education and awareness programme for NHS staff** on increasing choice and control, and on the Disability Equality Duty; promote good practice in enabling **choice and control over non-acute and continuing health care**
- **help people remain in employment** when they acquire an impairment or when an existing impairment or condition deteriorates; **increase access to volunteering opportunities**
- seek to ensure that current benefit and charging systems, and recent reforms, do not create any unnecessary barriers to independent living

- transform social care through delivering choice and control by, for example, individual budgets and direct payments, and through increasing access to advice, information and advocacy
- **promote a coordinated, strategic approach to investing in independent living for older disabled people**, and ensure that older disabled people's voices are heard and enable their participation in the development and delivery of services
- **seek to ensure a seamless transition into adulthood for disabled young 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 and
- promote more joined up working between health, education and social care to provide **timely and flexible support for families affected by parental disability**.

**The Government is committed to monitoring the progress of this strategy** using the new performance framework, in particular the Equalities Public Services Agreement. We will publish annual progress reports on the Independent Living Strategy, as part of the Office for Disability Issues annual reporting process. We will also **review the need for legislation** if sufficient progress has not been made against the outcomes by 2013.

## What does independent living mean?

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.'<sup>1</sup>

### 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

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).

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

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

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.

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.

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.



Image posed by models. Courtesy of [www.johnbirdsall.co.uk](http://www.johnbirdsall.co.uk)

## Independent Living case studies

We can post out a DVD of three disabled people (Lucy Mason, Ann MacFarlane and Jean Wilson) talking about independent living. Please contact the Independent Living Strategy team if you would like to use this, contact details are in section 5 of the consultation toolkit.

The case studies below are ones that we used when developing the Independent Living Strategy.

### **Laura**

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.

## **Hussain**

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.

## **Michael**

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.

## **Geoff**

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.

## **Lee**

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.

## **Steven**

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.

## **Margaret**

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.



Image courtesy of [www.johnbirdsall.co.uk](http://www.johnbirdsall.co.uk)

## **Ruth**

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.

## **Rhona**

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; and, mean that she and her partner receive help with other issues such as housing, harassment, employment, debt and benefits advice.

## Key Links

The launch of the Independent Living Strategy received significant press coverage.

We can post out hard copies of articles in the Times and the Society Guardian. Please contact the Independent Living Strategy Team if you would like to use these, contact details are given in section 5 of this toolkit.

We have given the links for key articles here:

**BBC Radio 4 'You and Yours', 3 March 2008 podcast:**

[http://www.bbc.co.uk/radio4/youandyours/items/03/2008\\_10\\_mon.shtml](http://www.bbc.co.uk/radio4/youandyours/items/03/2008_10_mon.shtml)

**Guardian Society, 5 March 2008:**

<http://www.guardian.co.uk/society/2008/mar/05/disability.equality>

**Times, 4 March 2008:**

[http://www.timesonline.co.uk/tol/life\\_and\\_style/career\\_and\\_jobs/public\\_sector/article3474559.ece](http://www.timesonline.co.uk/tol/life_and_style/career_and_jobs/public_sector/article3474559.ece)

**Community Care, 3 March 2008:**

<http://www.communitycare.co.uk/Articles/2008/03/03/107465/more-funds-will-boost-user-led-independent-living-strategy.html>

**Disability Now, March 2008:**

[http://www.disabilitynow.org.uk/latest-news2/independent-living-strategy-launched/article\\_view](http://www.disabilitynow.org.uk/latest-news2/independent-living-strategy-launched/article_view)

**Direct Gov, 3 March 2008:**

[http://www.direct.gov.uk/en/NI1/Newsroom/DG\\_072848](http://www.direct.gov.uk/en/NI1/Newsroom/DG_072848)

**Government News Network, 3 March 2008:**

<http://www.gnn.gov.uk/content/detail.asp?NewsAreaID=2&ReleaseID=357053>

**24dash.com, 3 March 2008:**

<http://www.24dash.com/news/Housing/2008-03-03-Independent-Living-Strategy-to-transform-lives-of-disabled-people>