



Office for Disability Issues

HM Government



# Involving disabled people

Government response to the consultation on implementation and monitoring of the Independent Living Strategy

**DWP** Department for Work and Pensions

Department for **Transport**

**(DH)** Department of Health

department for children, schools and families

**Communities** and Local Government

Department for **Innovation, Universities & Skills**

## Thanks

We would like to thank everyone who took the time and trouble to attend the consultation events that were run by the Office for Disability Issues (ODI) and those run by other organisations. We would like to thank especially those organisations that held consultation events on our behalf and most of all we would like to thank everyone who submitted a written response to the consultation.

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## Summary

The Independent Living Strategy (ILS) was co-produced with disabled people and we need to ensure that disabled people are actively involved in making the Strategy a reality and checking that good progress is being made. In this consultation we asked how best we should do this.

Having considered all of the responses, many of them detailed and thought provoking, we have decided to:

- **set up an Independent Living Scrutiny Group (ILSG) to review progress on implementing the ILS**
- **ensure that the ILSG works closely with the ‘Putting People First’ Reference Group**
- **develop a web-based and print resource to support disabled people’s involvement in Local Strategic Partnership Boards (LSPBs)<sup>1</sup>**
- **work with Equality 2025<sup>2</sup> to look at how we can best use and develop existing networks to form an effective ‘network of networks’; creating a two-way channel of communication between the Government and disabled people**
- **look at some of the options, for example specific courses, suggested by respondents for building leadership capacity**
- **take a number of actions to enable disabled people’s organisations to engage with the wider third sector agenda aimed at building the capacity of organisations, for example hosting a website with links to third sector capacity-building initiatives.**

We are very grateful to all those individuals and organisations who responded to our consultation, including those who held meetings to discuss the consultation questions and those who met with us to discuss our emerging proposals.

<sup>1</sup> LSPBs bring together key partners from the public, private and voluntary sectors to deliver the aspirations set out in the local community plan. LSPBs cover policies affecting particular groups, such as people with learning disabilities or a physical and/or sensory impairment, and older disabled people.

<sup>2</sup> Equality 2025 is the UK Advisory Network of disabled people (see [www.officefordisability.gov.uk/equality2025](http://www.officefordisability.gov.uk/equality2025)).

## Introduction

In March 2008 the five-year, cross-government ILS was launched. The aim of the 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.**

The ILS is jointly owned by six government departments and contains over 50 commitments aimed at delivering independent living for disabled people.

The Strategy sets out that progress towards the aims will be measured and reported on annually to the Life Chances Ministerial Group.

The Strategy was co-produced with disabled people and, in line with those principles, the launch of the Strategy also saw the start of a consultation to seek views on how best to involve disabled people in the implementation and monitoring of the Strategy.

This is the Government’s response to that consultation.

## The consultation

The consultation began on 3 March 2008 (when the Independent Living Strategy was launched) and ran until 20 June 2008.

The consultation asked a total of six questions:

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 ILS, for example by setting up an ILSG.**
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 ILS.**
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?**
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™<sup>3</sup> model, and/or whether there are other models we should consider.**
5. **We would welcome views on the best ways to assist implementation and monitoring of the Strategy at regional and local levels.**
6. **We welcome any other views on the Independent Living Strategy.**

As part of the consultation process we held two public consultation events, one in York and one in London. In addition, we produced a consultation toolkit to help groups of and for disabled people to hold their own consultation events. Members of the ILS team attended these events and a small budget was made available to help run them. Members of the team attended five events and we provided funding for four events.

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<sup>3</sup> 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 courses have been run in Britain since 1996 ([www.partnersinpolicymaking.co.uk](http://www.partnersinpolicymaking.co.uk))

## Responses

In addition to the information we received at the public consultation events in York and London we received 95 written responses to the consultation:

- 28 were from disabled people’s organisations
- 22 were from organisations for disabled people
- 12 were from service providers
- eight were from individual disabled people
- three were from parents or carers.

It was difficult to tell whether the remaining 22 responses were from an individual or an organisation and, if the latter, what kind of organisation.

We had six responses from groups representing older disabled people, two from groups representing Deaf people, four from groups representing people with visual impairments and eight from organisations representing people with learning disabilities. There was one response on behalf of neuro-diverse people.

Although there were no responses from any organisation that specifically represented people with mental health support needs or from those representing black and minority ethnic disabled people, the views of members of these groups were included in a number of the responses.

A summary of the consultation responses can be found at

[www.officefordisability.gov.uk/working/independentlivingstrategy.asp](http://www.officefordisability.gov.uk/working/independentlivingstrategy.asp)

While we welcomed comments on the Strategy as a whole (Question 6) the main focus of the consultation was on how to involve disabled people in the implementation and monitoring of the Strategy.

## What we did

In developing the cross-government response to the consultation the Office for Disability Issues (ODI):

- held a workshop for officials from across government departments
- held a workshop with some of the organisations and individuals who submitted detailed responses
- held a special meeting of the Independent Living Review's Expert Panel
- discussed the responses with Equality 2025.

This means that the ODI has worked in partnership not only with other government departments, but also with disabled people in order to develop the government's response to the consultation.

This has been an important illustration of how the ODI has been able to promote co-production, working in partnership with disabled people to develop policies to tackle the barriers to independent living.



## What we were told and the Government's response

### How to involve disabled people at a national level in oversight of the Strategy (Question 1)

The ILS sets out that progress will be monitored and reported on annually to the Life Chances Ministerial Group.

The Government is also committed to looking again at the need for legislation if not enough progress has been made by 2013.

The consultation suggested that an ILSG could be a way of involving disabled people in looking at the information that will be presented to the ODI Board of Management and the Life Chances Ministerial Group<sup>4</sup> and commenting on progress made. This would be a key way of helping disabled people to hold the Government to account.

The majority of respondents to the consultation were in favour of setting up some form of national ILSG. However, there was a strong feeling that a number of things must be done for it to be successful, and not to repeat previous mistakes. For example, lots of respondents said that the views and experiences of some groups of disabled people often remain unheard and unrecognised. They told us that this was particularly the case for disabled people from black and minority ethnic communities, for neuro-diverse people and for people with learning disabilities and/or communication impairments.

<sup>4</sup> The work of the ODI is overseen by a Board of Management and the Life Chances Ministerial Group (see [www.officefordisability.gov.uk/about/theministerialteam.asp](http://www.officefordisability.gov.uk/about/theministerialteam.asp)).

The consultation responses pointed to three possible options for setting up an ILSG. These were to:

- set up an ILSG to be made up of members of the Expert Panel<sup>5</sup> and Equality 2025, with some additional members who can cover the views of less heard groups; or
- set up an ILSG which tries to make sure that it has members from all of the different groups of disabled people covered by the ILS; or
- set up an ILSG that does not have members from all of the different groups of disabled people, but which does take account of the views of all of the different groups of disabled people covered by the ILS.

Respondents also told us that an ILSG should have a clear remit, be open and transparent in how it recruits people and in what it does, and have influence.

Although some respondents suggested ways to make sure that the ILSG fully represented all disabled people, many were of the view that achieving a fully representative membership of an ILSG would be impossible. They said it was far more important that people should have clear access to any group and that it was open about what it does.

The view was also expressed that members of the group should have the necessary skills and expertise to enable them to be fully involved with scrutinising progress on the ILS.

It was also clear from the responses we received, and from our discussions with key respondents when developing our proposals, that we need to be clear about the ILSG's relationship to Equality 2025 and that duplication of roles and activities should be avoided.

Having considered all of the options **we have decided to set up an ILSG**. Membership will be drawn from members of Equality 2025 and the Independent Living Review Expert Panel. In addition, we will try to ensure that less often heard groups such as people with communication impairments and disabled people from black and minority ethnic communities are involved.

<sup>5</sup> The work of the Independent Living Review was overseen by an Expert Panel (see [www.officefordisability.gov.uk/working/expertpanel.asp](http://www.officefordisability.gov.uk/working/expertpanel.asp) for details).

In selecting **members** for an ILSG we will make sure that members bring relevant knowledge and experience to their scrutiny role. We will also make sure that the ILSG has a clear and focused remit.

There were opposing views on whether family carers and service providers should be represented on the ILSG. We discussed the different options in some detail with those who we asked to help us in developing the Government's response. We have decided that the perspective of family carers should be included on the ILSG but not that of service providers. However, the ILSG should use its scrutiny role to promote awareness among providers of their role in delivering independent living and disabled people's experiences of the barriers to independent living.

The ILSG will be set up in early 2009. Its role and membership will be reviewed in the context of the evaluation of Equality 2025 which will take place late in 2009.

We are committed to the ILSG being an influential group, which will have an important role to play in the monitoring of progress on the ILS. It will receive the same monitoring data (unless, exceptionally, this is restricted) that is presented to the ODI Board of Management and the Life Chances Ministerial Group and will report its views to the ODI's Board and to the Ministerial Group.

Details of the ILSG will be posted on the ODI website ([www.officefordisability.gov.uk](http://www.officefordisability.gov.uk)) and will include details of members, the group's remit and minutes of meetings and reports. We will establish and publicise clearly-accessible routes for people to contribute their views to the ILSG.

## How to take advantage of current initiatives to involve disabled people and service users (Question 2) and how to support implementation at regional and local levels (Question 5)

We looked at Questions 2 and 5 together as they both seek to find out how disabled people can be involved effectively locally and regionally, and how they can implement and monitor the ILS. Most people when responding, either directly or indirectly, linked their responses to these points.

Some of the responses we received to Question 4 provided ideas for ways in which disabled people can be involved in implementing the Strategy.

We are trying to encourage disabled people – whatever their age, impairment group, access needs or geographical location – to be involved in implementing the ILS locally and regionally.

The general view of respondents was that local involvement of disabled people is patchy, not always accessible, and often doesn't include all groups of disabled people. However, there was a feeling that it would be best to work with these systems and improve them rather than invent new systems. This includes local involvement mechanisms that are not specifically about disability, but which could be usefully improved and worked with such as LSPBs.

Although the majority view of respondents was to build on existing mechanisms there was no clear consensus about how this should be done.

Having looked at the responses it is clear that there is no single course of action that will increase the involvement of disabled people locally and regionally, and work is required to achieve this.

We have identified a number of actions that are already happening, and others that we think will help.

### Involvement in the implementation of 'Putting People First'

'Putting People First' is a key part of the ILS. This three-year programme to transform adult social care will be the first public service reform programme which is co-produced, co-developed and co-evaluated, and recognises that real change will only be achieved if users and carers participate at every stage. As part of ensuring this, the Department of Health (DH) is establishing a Reference Group of users and carers.

#### **We think that there should be a close working relationship between the 'Putting People First' Reference Group and the ILSG.**

To promote this the ODI and the DH will ensure that there is some dual membership of the two groups and a system of formal reporting between them, with a particular focus on making progress on the involvement of disabled people in implementing 'Putting People First'.



### Disabled people's involvement in LSPBs

Responses to the consultation identified the need to support disabled people's involvement in LSPBs. Following further discussions on what is required and what is already available, **the ODI proposes to develop and disseminate a web-based and printed resource. This will include material aimed at increasing disabled people's capacity for involvement in LSPBs**, case studies and using methods such as video clips and DVDs to increase accessibility.

In developing this resource, the ODI will include and build on current guidance and resources (such as the Principles of Representation for third sector representation on LSPBs, and the ODI's forthcoming guidelines on involving disabled people).

The ODI will incorporate learning points from the progress made in involving people with learning disabilities in Learning Disability Partnership Boards. The ODI will also seek to form links with Deputy Regional Directors for Social Care and Care Partnerships and the work they are doing to support the role of local partnership boards.



### The role of Local Involvement Networks (LINKs)

A key development in improving the commissioning of services for disabled people is the establishment of LINKs.

LINKs are intended to play a vital role in encouraging and enabling a greater range of people to influence their local health and social care services. They will give all members of communities, including disabled people, the chance to influence health and social care services – whether they are run by councils or the NHS – and give citizens the chance to have their say in a much wider range of ways. Local authorities are under a duty to make contractual arrangements with a host organisation to enable, support and facilitate LINKs activities in every local authority area.

Some respondents voiced concerns that LINKs will not engage effectively with disabled people or address the issues that concern them, their health and wellbeing. These concerns may be addressed by the implementation of the guidance, issued by the DH, which includes a model contract for local authorities when contracting with a host organisation. This guidance makes clear that the host organisation should encourage participation from hard-to-reach and under-represented groups and communities. It says that LINKs should reach out to communities that are excluded from traditional decision-making processes in health and social care, to ensure that their views and opinions are heard and influential. The host organisation will need to demonstrate to the local authority how it is doing this, using measurements of its performance which will be agreed locally. A copy of the guidance and model contract are in the 'Getting Ready for LINKs' series of guides available via the DH website ([http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_077266](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_077266)).

The DH has also made available a progress checklist for LINKs, which emphasises that to be successful a LINK must enable different people to get involved in different ways that suit them. There will also be a more detailed self-assessment tool, which is in the final stages of development and will be available from the same website.



LINks are accountable to their local communities in a number of ways. One way is through the publication of annual reports in which LINks must provide details of what they have done to include the widest possible range of people and organisations in their work and to account for how they made decisions about the priorities they have concentrated on. A guide on Annual Reports has also been published. It is available at <http://www.nhscentreforinvolvement.nhs.uk/index.cfm?Content=196>

### Promoting the role of local User-led Organisations (ULOs) in local service development and delivery

The DH is leading work to encourage partnership-working between local authorities, third sector bodies and ULOs. This involves key stakeholders including the Association of Directors of Adult Social Services, the Local Government Association, the Commission for Social Care Inspection, the Office for the Third Sector and the ODI.

It aims to promote independent living, personalisation, community empowerment and social inclusion by facilitating engagement and partnership working between local authorities, ULOs and broader third sector initiatives. Further information about this initiative and the proposed Action Plan will be available in early 2009.

### Demonstration projects

The ODI is leading on two demonstration projects, as part of the ILS. They will run for two years from November 2008. One project concerns user-led support, advocacy and brokerage services and will work with ULOs in three localities. The other, a regional initiative based in the south east of England, aims to demonstrate how independent living can be delivered for older people with high support needs.

Both will support and demonstrate how service users can be involved in the delivery of independent living. The regional initiative has a particular emphasis on building the voice and involvement of older people with high support needs. The dissemination of lessons learnt – both during and at the close of the two-year projects – will assist in promoting the wider involvement of disabled people at regional and local levels.

### Is there a need for a 'network of networks'? (Question 3)

There are many existing networks of disabled people. Our aim is to draw these networks together to create a two-way channel of communication between the Government and disabled people. This would provide a substantial resource to draw on when attempting to encourage disabled people to be involved in implementing and monitoring the Strategy.

There was broad agreement among respondents that there would be value in a 'network of networks', but a general view that there should be further work to clarify its purpose and that a lot of effort must go into ensuring that it covers all groups of disabled people.

Although one option would be for us to create a new network structure, it was clear from many of the responses we received that rather than create new and additional structures we should build on what already exists.

Other respondents asked whether this was a role that should be performed by Equality 2025. Equality 2025 is in fact considering how a 'network of networks' would assist them to fulfil their role.

Having considered all of the responses it is clear that there is support for, and value in, establishing a 'network of networks'. **The ODI therefore intends to work with Equality 2025 to look at how we can, in line with what many respondents said, use and develop existing structures to form an effective 'network of networks'.** We will be paying particular attention to the inclusion of less often heard groups, for example black and minority ethnic disabled people, neuro-diverse people and those with learning disabilities and/or communication impairments.

## How to build leadership capacity among disabled people and their organisations (Question 4)

During the development of the ILS our Expert Panel advised us of the importance of building capacity among 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 the implementation of the Strategy. They suggested that Partners in Policymaking™ might be a useful model that could be adapted and we sought views on this in the consultation.

In general, there was support from respondents for courses and initiatives that had been developed and run by disabled people themselves. There was also a view that to be successful there needs to be a wide range of methods used to build capacity, both among those who are already involved and those who are not yet involved.

Although respondents gave examples of specific courses and activities that had been successful, there was no strong support for any particular model or existing course. However, most people felt that rather than commission something from scratch existing courses should be adapted and developed.

Having considered all of the responses we agree that a single approach is unlikely to succeed in building leadership capacity. **We have therefore decided that the ODI will look at some of the options suggested by respondents and work with existing course providers to develop their products for wider application.**

As part of this work we will also link with the work of the DH to build capacity within ULOs. We will also pay particular attention to how we engage with those not yet involved at a local and national level and, in particular, from groups of disabled people who are not currently benefiting from existing opportunities.

Current initiatives that will help to build the capacity of disabled people and their organisations to be involved at a number of levels include:

- The Citizen Leaders programme, funded by the DH, which supports service users' involvement by promoting leadership, information, support and mentoring. This includes work to enhance the programme's appeal and increase access to, and participation in the programme by older people.
- The DH programme aimed at fulfilling the government's commitment that, by 2010, there will be a ULO modelled on Centres for Independent Living in every locality.

The first wave of a Development Fund, set up in 2007 to support delivery of this commitment, provided grants to 12 local organisations and the DH is currently selecting sites to be involved in the second wave of funding. The DH will also consider what further work needs to be done to meet the Government's commitment.

- The Valuing People national advocacy fund which will include resources to strengthen leadership support for people with learning disabilities. Starting in autumn 2008, there will be a programme of leadership support in every region to build and strengthen self-advocate leaders and to support the development of strong advocacy support.

The Office for the Third Sector (OTS) supports a number of initiatives that aim to build the capacity of third sector organisations generally. For example, Capacitybuilders funds a range of work to enable organisations to access support on key issues such as campaigning, volunteering and income generation.

The Association of Chief Executives of Voluntary Organisations (Acevo) is responsible for delivering the work on income generation. This aims to address gaps in knowledge and skills among third sector organisations, enabling them to develop diverse and sustainable sources of income (see <http://www.improvingsupport.org.uk/>). In addition, Capacitybuilders also funds the National Hub for Finance, which provides a useful resource for organisations wanting to know more about fundraising through tendering for public service contracts (see <http://www.financehub.org.uk/default.aspx>).

OTS also funds Futurebuilders England Ltd (<http://www.futurebuilders-england.org.uk/>) to administer the £215 million Futurebuilders Fund. Futurebuilders provides loan- and grant-based finance to help third-sector organisations develop their ability to deliver public services.



However, it is not clear whether disabled people's organisations have been able to take full advantage of these initiatives. **We therefore propose a number of actions to enable disabled people's organisations to engage with the wider third sector agenda and to help ensure that these organisations gain access to the resources available for third sector development.** These actions build on the many ideas and views that people gave us in their responses to our consultation, and also on our more detailed discussions with key stakeholders.

- The ODI will jointly host an event with the DH and the OTS which will aim to:
  - share information and build knowledge of relevant initiatives and projects – both specific to organisations of disabled people and those more generic
  - ask participants how to get the most out of existing initiatives
  - identify issues and gaps in capacity-building work, particularly around the raising of awareness within the commissioning process.
- The ODI will host a website with short descriptions and links to the various third sector capacity-building initiatives, with the aim of creating better awareness among disabled people's organisations of the opportunities available. This website will also help to disseminate knowledge of the government's wider agenda on community empowerment and the capacity building of the third sector.
- The DH and the ODI will work with the OTS to help ensure that work to build the capacity of the third sector encompasses ULOs and, in particular, raise awareness of the specific barriers that ULOs face to engaging in commissioning.
- The ODI will promote the drawing up of a list of consultants who are experienced in both capacity-building third sector organisations and the particular needs of ULOs. We will explore the need for specific training in order to build this type of dual expertise. In doing this we will liaise with the National Council for Voluntary Organisations and its Directory of Approved Consultants.

## Conclusion

The ILS was developed in partnership with disabled people and it is important that they are fully involved in making the Strategy a reality and checking that good progress is being made. We consulted disabled people on the best way to do this.

With the help of disabled people we have considered all the options and have decided to:

- **set up an ILSG to review progress on implementing the ILS**
- **ensure that the ILSG works closely with the ‘Putting People First’ Reference Group**
- **develop a web-based and print resource to support disabled people’s involvement in LSPBs**
- **work with Equality 2025 to look at how we can best use and develop existing networks to form an effective ‘network of networks’ creating a two-way channel of communication between the Government and disabled people**
- **look at some of the options, for example specific courses, suggested by respondents for building leadership capacity**
- **take a number of actions to enable disabled people’s organisations to engage with the wider third sector agenda aimed at building the capacity of organisations, for example hosting a website with links to third sector capacity-building initiatives.**



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HM Government

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We welcome feedback on this report.

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