

# **Independent Living Strategy Implementation and Monitoring Consultation**

## **Summary of responses**

Summary of consultation responses, and feedback from events.

## **The consultation process**

The consultation questions were agreed with the Expert Panel of disabled people who advised the Independent Living Review. In planning the consultation process the Office of Disability Issues held a meeting with members of the Expert Panel, Equality 2025 and other disabled people to discuss both the consultation questions and the consultation process.

We

- published the consultation on the website, inviting responses
- emailed all those individuals and organisations we were in contact with during the Independent Living Review
- held two large consultation events, one in York the other in London
- produced a consultation toolkit to help organisations to respond and/or organise their own consultation events
- offered to pay expenses for disabled people's organisations that ran their own events and offered to attend events or meetings: we attended 6 Meetings, and provided funding to 4 organisations.

We have received 95 written responses to the consultation and we have also written up the feedback we received at the two large events, from the flipcharts and notes taken on the day. All this has been published on our website:

<http://www.officefordisability.gov.uk/working/independentlivingstrategy.asp>

## **How did we go about writing this summary?**

Different people at the Office for Disability Issues looked at the responses in different ways, to make sure that every point and each response was captured. For example, one person looked at each question in turn without knowing who the responses were from, while another looked at the responses in order. One person also looked specifically at the responses from under-represented groups of disabled people (such as people from black and minority ethnic communities) so that we were sure that these were recognised.

We then held a meeting of the whole team to see if our draft summaries highlighted the most important themes, and that nothing vital had been left out or summarised incorrectly.

Following this meeting we drew up a draft of the final summary, which was circulated for comment before being finally agreed on.

We have tried to highlight the themes that were most commonly expressed in the responses, and have also taken care to include the views of those groups which are most often ignored. As part of developing the Government's response to the consultation, we are holding a workshop and meeting with some of these groups to discuss their responses.

This document represents the views of the people and organisations who responded to the consultation. The Government's official response to the consultation will be published later in the year.

## **General themes about how to involve disabled people in implementing and monitoring the strategy**

Responses to the consultation were wide-ranging and covered lots of issues, with many different opinions expressed. However, some common concerns and key themes emerged.

## **Need for strong disabled people's organisations**

It was strongly felt that properly supported local user-led organisations and disabled people's organisations are vital for the implementation of the independent living strategy. A number of respondents highlighted the difficulties that some of these organisations are facing and that some have had to close. They stressed that, in order for the Strategy to be successful, these difficulties must be addressed.

## **The importance of being inclusive of everyone**

An equally strong message was that there is a need to be inclusive of all groups of disabled people and that this means making sure that all ages and all impairment groups are included, as well as people from BME communities and from rural as well as urban areas.

## **Lack of awareness**

It was felt that there is a lack of awareness of independent living, amongst both service providers and disabled people. Respondents said there needs to be a real culture change for the strategy to work. Some organisations and individuals pointed out that it is particularly important that those working with, for example, people with dementia, understand how independent living principles apply to their services.

## **Work with what's there**

Despite criticisms of existing arrangements for involving disabled people, it was generally felt that it would be better to build on and improve these rather than creating new ones. Respondents said that it is vital to work hard to achieve genuine inclusiveness and accessibility, and that any ways of involving people must be properly run, with clear plans, outcomes and resources. Above all there must be transparency and accountability.

## **Need for advocacy**

Some respondents told us that, for disabled individuals to be empowered, there is a need for independent advocacy and for

better access to complaint systems. They felt this was crucial for the successful implementation of the Strategy, and particularly important for some disabled people, such as those with significant learning disabilities or communication impairments.

## **Two-level approach to representation**

A number of people said that there should be a two-level approach to ensuring that the voices of disabled people are heard. They thought that, as well as genuinely representative organisations, there must also be ways for individuals to have direct input, and that there should be training and support for people to do this.

The next section is a more detailed summary of the responses, taking each question in turn.

## Questions

**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.”**

Of the replies that addressed this question directly, the majority were in favour of some form of national Independent Living Scrutiny Group. However, there was a strong feeling that a number of issues must be dealt with for it to be successful, and to not repeat previous mistakes. In many cases these concerns were similar to the reasons given for not having a Scrutiny Group by those not in favour.

### **How a Scrutiny Group should be made up**

Most replies said that the group should be made up of disabled people. However, some also suggested that informal carers and family members should also be included.

There was strong agreement that the group should be representative of all impairments, and be sure to include traditionally over-looked groups such as neurodiverse people, people with learning difficulties and people with challenging behaviour (or their representatives). It should avoid appointing the same people that always seem to be on these kinds of groups.

Some said that there should be a democratic election system to ensure fairness. However, a few commented that true representation is, in practice, difficult or impossible to achieve. There was general agreement that what is needed is transparency and accountability.

There was also strong agreement that care should be taken to ensure the involvement of disabled people from black and minority ethnic communities, as well as younger and older disabled people, and people from across the country, including rural areas.

Some people suggested that organisations responsible for commissioning and delivering services should also be represented, such as local authorities, and voluntary and private sector services.

### **How a Scrutiny Group should be organised**

There was strong feeling that the group must have enough resources and support to run effectively. Some stressed that members should be paid.

A common message was that the group's organisation and communication must be flexible enough to be accessible to all. Some suggested that this might mean working in different ways, such as running smaller sub-groups, using web forums and telephone meetings, and, for example, being creative about engaging younger disabled people.

Some respondents stressed that the group should take account of existing organisations and networks, and find ways to receive input from local groups and individual disabled people. Some people felt there should be regional scrutiny groups. All this input should then feed into the national group.

### **Remit, accountability and influence**

A number of respondents said that the group's remit must be clear, and some emphasised that it should be careful not to overlap with the responsibilities of Equality 2025 and the Equality and Human Rights Commission. Generally, it was stressed that reporting procedures must be clear, and there should be adequate feedback mechanisms to disabled people.

Respondents said there should be clear ways to monitor success and measure outcomes. These should be flexible and creative, to ensure accountability to disabled people.

Generally, there was a concern that the group should not be tokenistic and that it must have real political influence. Some respondents said that the group should have the power to enforce decisions.

Most respondents said the group should hold central Government to account, but also be accountable to disabled people, with clear way to show that people have been listened to. Some respondents emphasised that the group's meeting agendas and minutes should be publicly available, and there should be ways of making sure its role is widely known to demonstrate that people have been listened to.

### **Opinions against a Scrutiny Group**

The replies that were strongly against an Independent Living Scrutiny Group focussed on the need for direct representation and monitoring, with a number of suggestions offered for how this could be achieved; for example, through a regular questionnaire, with creative ways to access and complete it, or by writing to people on disability benefits, or by using existing organisations.

There was also a feeling that similar groups already exist, and that these have failed to bring about improvements in people's lives. These respondents felt that creating another group will just repeat the frustration that disabled people already experience.

**Questions 2 and 5: “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.” “We would welcome views on the best ways to assist implementation and monitoring of the Strategy at regional and local levels.”**

These questions were similar, and responses were similar too, so we've addressed them together. The issue is about how effective the involvement of disabled people is locally and regionally, and how it can be used to implement and monitor the Independent Living Strategy.

The general view 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.

Local Involvement Networks (LINKs) are an example of this. Some respondents said that they are potentially useful, but that they must be made more inclusive and accessible. Some suggested they should be run by user-led organisations, and that they should connect with other organisations and initiatives that involve service users.

More generally, it was felt that local disability groups need more influence, and should be properly funded and resourced. They should reach out to the less heard groups of disabled people, be better at telling people what they are doing, and should link with other local groups to avoid duplication. Some respondents said there should also be stronger user-led ways of evaluating local services.

There were also suggestions that the monitoring and implementation of the strategy should link to local and regional Government; for example, to local councils' mechanisms for monitoring their equality schemes, or through links with the Government Offices for the Regions. There should also be links to Public Service Agreements, Local Strategic Partnerships and Local Area Agreements.

There was much emphasis on the important role of organisations led by disabled people themselves. However, it was also stressed that many of these organisations are struggling to survive and will need sustainable funding if they are to play their part in monitoring and implementing the strategy. The need for strong leadership was mentioned (see also question 4), with suggestions for an Independent Living Strategy champion at both regional and local levels.

There were some examples of local involvement working well. For example, Learning Disability Partnership Boards were mentioned by a number of respondents.

### **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?”**

There was broad agreement for this, but many of the same concerns were raised over and over again. As with question 1, the concerns of those broadly in favour were often the same as the reasons given for not being favour.

In particular, respondents said that work must be done on giving a voice to those people who do not belong to a network, to prevent the creation of an elite group which excludes others.

There was a feeling that it would be best to build on and join up existing networks run by disabled people rather than imposing something new and over-bureaucratic from above.

Generally, respondents felt that existing networks should be made fully accessible, representative, and reflect the diversity of disabled people. Some respondents pointed out how particular groups, such as people with learning difficulties, or older disabled people, are often unintentionally excluded from groups representing disabled people generally.

Again, the point was strongly made that many existing groups are under-funded, under-resourced, and have to spend a lot of their time applying for (often short-term) funding rather than working on services. Respondents said this must be addressed if a network is to be successful, not just an additional burden.

Nevertheless, lots of examples of good practice were received, and there was a feeling that these should be built on and not lost. The British Council for Organisations of Disabled People was mentioned as a good model that has collapsed through lack of funding. Reinstating it was suggested. A number of organisations who responded run their own networks and offered to assist with a ‘network of networks’, and in particular to assist with making such a network accessible to all.

The view was expressed that a 'network of networks' must be clear and simple so as not to lead to confusion, duplication of work and dilution of its purpose. One idea suggested was a pyramid structure of existing organisations – local forums feeding into regional, feeding into a national network.

Some respondents said that the network itself should be monitored and have a clear and defined purpose and accountability. There were lots of suggestions for how to do this.

Finally, a number of people commented that Equality 2025 should be performing this networking role but currently isn't. Some people felt this was because the original recommendation in the 'Life Chances' report for a National Forum of Organisations of Disabled People has not been implemented. Some respondents said that for Equality 2025 to fulfil its role it was important for it not to be remote, that it needed to make sure its remit and workplan were clear, and that its work was informed by the voices of disabled people

**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 TM model, and/or whether there are other models we should consider.”**

There were mixed feelings about the Partners in Policy Making model. There were more positive than negative responses overall, but very few were completely positive about it. Those broadly in favour expressed similar concerns to the reasons given by those completely against it.

Mainly these concerns focussed on the course not being sufficiently accessible or inclusive. Some people thought that it was led by parents and carers, rather than being led by disabled people, and that it was too long and complicated.

Generally, though, there was a feeling that it is best to build on and improve existing courses and resources, to make them more inclusive and accessible. Several examples of good initiatives were given, some of which have been developed by disabled

people, while other examples were courses that have been developed for the voluntary and community sector generally. Others stressed the importance of courses run by disabled people themselves.

The responses seem to indicate that a wide range of methods of capacity building should be available as different groups of disabled people have different requirements.

More widely, responses mentioned a need to empower individuals alongside capacity building leadership. Connected to this, respondents said there is a need to raise awareness of independent living, the Disability Equality Duty, the social model of disability, and the services and support that are available from disabled people's organisations.

Others mentioned the need for courses to include training on how local government works, for capacity building to start in schools, and the need to link training to the work of disabled people's networks and organisations. A number of respondents felt strongly that any capacity building initiatives must use disabled people's organisations and build on what they have found useful. Properly funded and resourced user-led organisations were therefore felt to be vital.

Some respondents commented on the nature of leadership. It was pointed out, for example, that good leadership requires not just the active consent, but also the empowerment of those being 'led.' Others highlighted a need for strong Government leadership, to prevent any one group having too much power.

### **Question 6: "We would welcome any other views on the Independent Living Strategy"**

There was a very strong feeling that the strategy needs to be backed up with increased funding, and, more importantly, by legislation. Many felt that without legislation there will be very little change, despite the good intentions and strong policy commitments of the strategy.

One theme was the difference between improving the systems of social support and the need to ensure full access to those

systems. Some respondents said that even if the system worked perfectly, this would not be true equality until it could be accessed by everyone. Achieving this would mean reforming the eligibility criteria for support, so that it is not just people with critical or substantial needs that receive services. It would also mean extending independent living principles to some less heard groups and addressing their particular requirements for support.

Respondents also stressed the need for better provision of information, as well as advocacy support for people to access the services they need.

Many of the responses talked about specific access issues and barriers to independent living that people face in their lives. These included:

- inadequacies in services provided by local councils,
- problems with direct payments,
- the disabling assessment procedures for claiming benefit,
- poor access to equipment and services, such as communication equipment, speech and language therapy, mobility equipment and computers, and
- the inaccessibility of many aspects of housing, transport, leisure facilities and the built environment.

There was a strong feeling that much more needs to be done in terms of joined-up thinking, by central and local Government and other agencies, in order to address these issues. Respondents said there is a clear gap between national policy and local implementation. Many responses gave good practical solutions to specific problems, and examples of good practice in their local area.

There was also a strong feeling that some groups are still being excluded more than others, both locally and from the Government's national strategy. In particular, neurodiverse people and people with learning difficulties feel particularly excluded, and gave strong criticisms of the way the consultation had been run. The exclusion of people from black and minority ethnic communities was also mentioned regularly. In addition, a number of respondents emphasised that barriers to, for example transport, are not always physical but can include negative attitudes of

transport providers towards people with mental health support needs.

There were many practical suggestions about specific sections of the strategy, many of which welcomed the Government's commitments but suggested ways they could be expanded to include other groups or services, or made more effective. Some felt that the strategy, whilst welcome, doesn't go far enough. There was also some cynicism about implementation.

We have not listed here the detailed additions that some respondents suggested should be made to the Strategy but they have all been logged by the Office for Disability Issues. Where appropriate the suggestions have been raised with the government department with responsibility for the area concerned, and all of them will inform ODI's role of promoting full equality for all disabled people.

## **In conclusion**

Thank you for all your responses and for the offers of help and support several of you made. We do not underestimate the task before us, and over the next few months will be looking at how we can use what you have told us to plan for the next stage.