

# **Independent Living – Making it Happen**

## **Summary Report of Consultation Events**

### **What is it all about?**

The Scottish Government has asked us – ODS Consulting – to review the Independent Living Programme and set out what needs to change in future.

This programme promotes independent living for disabled people. By independent living we mean having the freedom, choice, dignity and control to live your life the way you want to. This includes at work, at home and in your community. At the moment, this isn't always possible for disabled people.

As part of this work, we ran three informal events for disabled people and people with an interest in independent living. This short report explains the main points people made to us about independent living during these events.

### **What did we do?**

We ran three events at:

- Glasgow Centre for Inclusive Living – attended by 28 people
- Perth Concert Hall – attended by 20 people
- Edinburgh, Norton Park – attended by 27 people.

Each event was designed to encourage as many people as possible to have their say. The events focused on four topics, and each person was asked to pick two topics to discuss during group conversations. The topics were:

- Housing – your home
- Care at home – and what happens when you move home
- Communicating - in a way that everyone can take part
- Advocacy – helping you to speak up for yourself.

In total there were five conversations about housing, six about care at home, six about advocacy and seven about communicating. Many people also talked to us about wider issues to do with independent living, and we will include this in our work.

## What did people say about housing?

People discussed:

- In an ideal world, what does accessible housing mean to you?
- What stops these things from happening just now?
- What would help these things to happen?

People said:

- Disabled people want choice, safety and a good location – just like everyone does.
- There is a lack of affordable and suitable housing for disabled people, and it can be difficult to find out about.
- Having a home which is affordable is very important – especially as disabled people are more likely to be economically disadvantaged and their homes are often more expensive.
- Homes should be designed in a way which meets current needs but can be adapted in the future. All housing should be built to accessible standards and be accessible for wheelchairs.
- At the moment, people are not well involved in planning the alterations and adaptations they need.
- Better access to housing information and advice is needed. There are currently lots of organisations, and people don't know where to go.
- Housing and support services are often not well linked, and lots of different people can be involved in making a small change happen.

People wanted to see:

- More accessible housing available.
- Better information and fairer access.
- Good information, advice and advocacy.
- Funding for adaptations and more of a focus on the individual and their needs.
- Awareness raising and training for people who work with disabled people.
- Service users and providers working together to design and deliver services.
- Joining up housing, social care and health budgets.
- Raising incomes – through employment and changes to the benefits system.
- A common framework for measuring progress which is clearly understood.

## What did people say about advocacy?

People discussed:

- When do you think people need support to speak up for themselves?
- How can this kind of support help?
- What would make it easier for people to get this kind of advocacy support?

People said:

- Advocacy is especially important for disabled people when they are trying to get support, an aid or adaptation, or at particular times in their lives.
- People should be able to access advocacy throughout their lives, when they need it.
- Advocacy can help people make informed choices, develop confidence and express their views themselves. Where appropriate it can involve speaking on a disabled person's behalf.
- Skilled advocacy is important – people need to have the right skills and approach, and understand disability and individual needs.
- Building individual relationships with an advocate is important.
- Independent advocacy is important. Disabled people's organisations or disability organisations can play an advocacy role.
- Advocacy is not available to everyone who needs it and there are inconsistencies between different areas, and for different groups.
- Many people don't know what advocacy is or where they can access it.

People wanted to see:

- Better information about advocacy and improved awareness – among disabled people, their families and professionals.
- Better and more consistent advocacy services across Scotland – for all disabled people.
- The use of communication aids and adaptations in advocacy services – so that they are really accessible for everyone.
- More group or peer advocacy (where disabled people work together to speak out for individuals or groups of people) and citizen advocacy (where an individual is matched to a disabled person over a long time)
- High standards of advocacy, and well developed training for advocates

## What did people say about communication?

People discussed:

- When and why do people feel excluded from communication?
- What would the ideal situation look like?
- What could help to make this happen?

People said:

- Sometimes people are excluded because of a particular impairment. But personal characteristics and circumstances can also affect communication – such as age, family situation, ethnicity, the area you come from, and who else is involved in your life.
- Bad communication can have a severe impact on disabled people – particularly when it involves decisions about benefits and finance, support, employment and health, at times of illness, when people are isolated, in emergencies or when dealing with ‘professionals’.
- Although technology has helped some people be less excluded, people who are not comfortable or able to use technology or the internet are becoming more excluded.
- The new Disability Living Allowance and welfare assessment process are key areas for concern.
- How inclusive communication is varies between services and individuals.

People wanted to see:

- A change in attitude – disabled people, their carers and professionals need to work together as equals. But stigma and power imbalances need to be overcome.
- Greater consistency – across Scotland and across a range of services. There is a need for clearer accountability and leadership between national and local government. This might involve national consultation or a national strategy.
- There needs to be closer working between different agencies with the disabled person at the centre.
- Better use of existing tools and guidelines in inclusive communication. Many already exist – but people need to be made aware of them and use them.
- Services need to work with disabled people to identify their communication needs, and meet these.

## What did people say about moving home and care?

People discussed:

- Are there problems when people receiving care want or need to move home?
- What would the ideal situation look like?
- What could help to make this happen?

Many people raised general issues about the quality and availability of care.

People said:

- Having the right care and housing is very important – it can make people more confident and support them to live independently.
- Not everyone is getting the care they need. There are big differences between areas, and people often don't know what is available.
- There is a lack of accessible houses which meet peoples' needs.
- The processes when applying for benefits, housing or care can be complex and difficult to negotiate. Changes to the benefits system are likely to have a negative impact on independent living.
- People are different and have different needs – but they are often thought of as all being the same. Care needs to be more focused on the needs of an individual.
- There can be an overreliance on family to support disabled people.
- Often disabled people have to deal with lots of different individuals to arrange or change the care they receive.

People wanted to see:

- More support for people to have their voice heard. This might involve peer support and better access to advocacy services.
- Better information and advice – so that people are aware of what they can access and how to do that.
- Improved attitudes – so that the public and people working in services can deal with disabled people better. This might require training or education.
- Better access to the right kind of home.
- More consistency between services and across areas – both in terms of what people are offered and how care is assessed.
- More flexible care which is focused on the needs of the individual.
- A key contact who will support a disabled person through the process – dealing with housing, care and any other issues. This might be an information officer, a GP or social worker.

## **What else did people say about independent living?**

Some issues came out from different groups, or were wider points about independent living. People said:

- Even if these four areas are improved, there needs to be enough funding available to support people to live independently. This includes both individual benefits, and funding for services or organisations which support disabled people.
- Disabled people can experience a 'postcode lottery'. In some areas, housing, support and services are good but in other areas they can be poor. Application and assessment processes are often different. And having so many different approaches can make it difficult to understand what you can access, and how.
- Attitudes are important. People said that the public, decision makers and staff often don't understand disability, how to communicate with disabled people, or support independent living.
- Having services, assessment processes and support which are person centred is very important. Everyone is different – they will have different aspirations and needs.
- People should be able to access support and advice when they need it. But sometimes – for example when people are experiencing a change in circumstances or crisis – people need support even more.