



Independent
Living in Scotland
Inspire • Involve • Invest

An essential guide to Independent Living in Scotland



From what to eat to where to live, life is about decisions – being able to choose what you want to do and how, where and when you want to do it.

But, as a disabled person, the right to have control over your own life is more often than not denied.

‘Independent living means disabled people of all ages having the same freedom, choice, dignity and control as other citizens at home, at work, and in the community. It does not mean living by yourself or fending for yourself. It means rights to practical assistance and support to participate in society and live an ordinary life.’

This is the definition of independent living, developed by disabled people, and adopted by the Independent Living in Scotland project

No ifs, no buts – we are all entitled to freedom, choice, dignity and control

Q. What is independent living in everyday terms?

A. Independent living means looking at the bigger picture. It’s about having equality of opportunity on a par with everyone else, and the freedom, choice, dignity and control to determine how that opportunity is delivered and used.

Independent living covers many different elements of a person’s life, including:

- the environment and transport
- personal support and services
- economic, social and public life
- the impact of political and service structures

These elements must come together as a whole for disabled people to achieve control over their lives.

The right to a bright future

A number of disabled people have come together to form the Independent Living Movement

The Movement promotes the idea of independent living; along with a number of entitlements, which, if met, would enable disabled people to participate fully and equally in society.

The basic rights of Independent Living

- Full access to our environment
- Fully accessible transport
- Technical aids and equipment
- Accessible and adapted housing
- Personal assistance
- Inclusive education and training
- An income, including income within the state-benefit system for those unable to work
- Equal opportunities for employment
- Accessible and readily available information
- Advocacy and working towards self-advocacy
- Counselling, including peer counselling
- Accessible and inclusive healthcare provision
- Communication and appropriate support for communication



Let's make them happen...

Moved to act

You've read the rights,
now make them reality

The Movement

The Independent Living Movement took off because disabled people are frustrated at the lack of control they have over their own lives. The Movement is led by disabled people for disabled people. It aims to bring about change by establishing that 'disabled people' are disabled by the way society treats and excludes them.

The Movement campaigns for the principles and practices of independent living to be the cornerstone of mainstream social policy and service delivery.

In June 2008, the Scottish Government announced funding to develop independent living in Scotland, including funding specifically to develop the Movement.

The Independent Living in Scotland (ILiS) project was born.



Making it happen

The ILiS project aims to strengthen and develop the Independent Living Movement throughout Scotland and to support the involvement of disabled people in shaping the Scottish Government's approach to independent living. Representatives from the Independent Living Movement in Scotland guide the project.



How will it achieve this?

We will establish links with disabled people and their networks and support them to promote the goals of independent living. We will work with the Independent Living Movement to support them to help policy makers and service providers gain a better awareness of independent living.

We will also work with the Scottish Government through their Independent Living Reference Group and contribute to their wider work to involve disabled people across the work of the Scottish Government. Change starts here.

‘Equality can be achieved through changing environments, organisations and attitudes, and empowering disabled people to achieve self-determination’

Best supporting role?

Independent living requires fully functioning personal support, and services that enable choice and control and no, we're not there yet...

How it should be:

Health and support services that meet disabled people's needs.
That's support services – not social 'care'.

How it is:

Put simply, needs are not being met. Many hospitals and other health services lack accessible facilities, and support services and social 'care' vary from area to area both in quantity and quality. There is a lack of provision for the needs of specific groups, such as older or younger people and people with conditions like Alzheimer's. In some cases, disabled people are bearing the financial brunt of funding their own support. Different providers often don't work together to offer joined-up services.

'Over 70% of local authorities provide services only to those whose needs are considered "critical or substantial"'

How it should be:

Self-Directed Support available across Scotland.

How it is:

It's not who you are, but where you live and what you know – the delivery of Self-Directed Support and direct payments has become a postcode lottery. Self-Directed Support is where disabled people use money (such as a 'direct payment' from their local authority or 'individualised budget' from a number of sources) to choose and pay for services themselves. This should give disabled people more control and flexibility; but the systems for getting the money can be very bewildering and budget cuts mean there's not enough money available or advice on how to use it. Also, many professionals don't fully understand Self-Directed Support themselves and don't promote it.

How it should be:

Information and support for all.

How it is:

Information is power, but the provision of information and advice is left wanting. In addition, there is a lack of awareness of, or access to, support amongst disabled people. There are also insufficient links between organisations led by people with different impairments.

'Self-directing my care has enhanced my dignity'

Iain Williamson, from Kelso, says control is the key to his achievement of independent living

"In 2005, I had a major stroke, and lost function to my left arm and leg. By October 2006, I had learned to walk short distances with a stick. At first, I needed help with personal grooming and putting on my ankle support device. But, as time passed, my capabilities improved.

I got money from the Independent Living Funds (ILF) to employ personal assistants to help me with leisure activities. This was so successful that I eventually employed one of my PAs directly to provide my support services and access to leisure. These are funded by direct payments from the local authority, as well as Independent Living Funds (a Non Departmental Government Body, funded by central government and sponsored by the DWP).

I have achieved a good quality of life, going out where and when I want. This has included swimming, shopping and visits to restaurants, as well as three foreign trips in the last year. Self-directing my care has given me responsibility for my daily living and enhanced my dignity.

I have experienced some negativity from healthcare and community care. One patronising community occupational therapist sought to restrict my activities, in case I had an accident for which she would be responsible.

A joined-up approach to rehabilitation would make a huge difference.

The appointment of one individual to co-ordinate all rehabilitation activity would provide the benefit of co-ordinated healthcare and occupational-therapy services. Indeed, I believe every person in my situation should have input to a rehabilitation plan with stretching, but achievable, goals."



And action!

Here's what needs to happen...

Disabled people are calling for urgent changes relating to personal support and other services, including:

the enforcement of relevant legislation and policy; the identification of required developments; service user involvement in all relevant bodies and developments; all initiatives, including training of support and other staff, to be based on the policies and practices of independent living; and the issues relating to the inclusion of all disabled people in services and service development to be considered.

And, more specifically...

To create support and services which are personalised, self-directed, rights-based and joined-up with opportunities for assisted decision-making for those who require it. Early identification of those at risk of crisis and early intervention are needed, as well as access to self-management of long-term conditions. A framework of minimum entitlements should be set up, and there should be development of specific initiatives, such as health checks and access to adaptations and support for informal carers. Self-Directed Support should be actively promoted and there should be backing for users to support each other. There needs to be a strategic and consistent approach across Scotland.



Going places, using spaces

Transport, the built environment and housing should be affordable, appropriate and accessible. Guess what – they're not...

How it should be:

A transport system that works for disabled people.

How it is:

Public transport and facilities are often inaccessible, and there is variation across Scotland in the provision of on-demand transport. Travel costs can be high and concessionary-fare schemes limited. Not enough travel training and support is provided; information is often inaccessible; and some people are uncertain that their travel needs will be met when they turn up at the bus stop, station or airport. Add to that services at inappropriate times and difficulty caused by having to book in advance, and it is clear that disabled people don't have equal access to transport.

How it should be:

Buildings and public spaces that meet disabled people's needs.

How it is:

Across Scotland, many buildings pre-date current legislation and building standards. In most new buildings, there is a lack of total and limited funding for improvements. There are few opportunities to involve disabled people in designing places, and there is a lack of understanding by professionals.

How it should be:

Housing that is fit for disabled people.

How it is:

There is currently not enough accessible and affordable housing. It's a fact that proportionally more disabled people than non-disabled people are living in social rented housing, and poorer or unsuitable housing. Not only that – disabled people are experiencing problems, such as delays and funding when adapting housing to their needs. Overall, there is a lack of information. The social housing application process is inaccessible to many, including people with learning impairments.

'A better house would mean independent living for me'

Karena Youngson, from Aberdeen, describes what makes her tick (and what makes her sick)

"I'm a mother, a full-time student doing my Highers, I'm in a wheelchair – oh, and I host karaoke once a month.

The transport in Aberdeen can be good, but some people can be unpleasant. I also find a lot of places are not accessible. If I want to go for a meal, there are only a few spots I can go. It's the same for a night out.

Aberdeen College has been great in helping me get on with my education. I had difficulties with some of the desks, but, once I brought this to their attention, they bought a table that was perfect for me to study on. Then my needs changed and I found that I couldn't write for long periods, so the college lent me a laptop to overcome this problem.

I was shy back then. Their support has made me a more independent person. I'm now the disability representative for the Aberdeen College Students' Association.

My housing situation is not ideal. I live in a one-bedroom house – my son sleeps in the bedroom, and my partner and I are in the living room. I was offered another house, but it would have been too small for me to get about in. If I was in a better housing situation, I would say I would have achieved independent living. This would be the icing on the cake, as the saying goes."



And action!

Here's what needs to happen...

Disabled people are calling for urgent changes relating to the environment and transport, including:

the enforcement of existing legislation and regulations; the identification of required developments; involvement in developing policies; disability-equality training for transport, planning and housing staff; and the needs of all disabled people to be considered.

And, more specifically...

Transport:

It's clear that, for disabled people, the transport system isn't getting anywhere. All types of transport provision need to be developed. Local transport measures must also be implemented (for example, an accessibility requirement for taxis), while other necessary improvements include transport information and support, travel training for disabled people, concessionary-fares schemes and extension of free travel.

The built environment:

Buildings? Fortresses, more like. There needs to be more support for access panels of disabled people in planning the built environment. Well-designed neighbourhoods would give access to all aspects of the environment, and the development of incentives would promote good practice, such as a 'national accessible design award scheme'.

Early implementation of the Disability Discrimination Act should be encouraged.

Housing:

Home is where the heart is, so why are disabled people's rights being ignored? More accessible and appropriate housing is needed; public-sector housing and new housing should meet agreed standards, including a higher proportion built to wheelchair-accessible standards. The removal of adaptations from homes must be stopped, adaptations services developed and funding provided. In addition, there must be more low-cost home-ownership schemes, better information and support, and more accessible housing registers.

Work, rest and play

Wanted: full participation by disabled people in economic, social and public life

How it should be:

Disabled people having the chance to be active and valued at work.

How it is:

Work is not working for disabled people. Statistics show that they are less likely to be in work than non-disabled people. They may also experience discrimination when in work. Gaps in information don't help matters, and inappropriate attitudes amongst some employers can make life very difficult indeed.

How it should be:

Disabled people receiving an appropriate income.

How it is:

Far from rosy. Low income and benefit levels are commonplace, while finances continue to be depleted by the high costs arising from items and services, like adaptations, social care, as well as mobility and communication aids. Disabled people are more likely to live in poverty than non-disabled people.

How it should be:

Equality in education and training.

How it is:

Equality? If only. Poorer education is more often experienced by disabled people than non-disabled people. This can be caused by lack of physical access and negative attitudes. A lack of information and support also means many people are not aware of the opportunities available to them.

How it should be:

Disabled people being fully involved in public life.

How it is:

Disabled people have limited involvement in positions of authority, public appointments and volunteering. Lack of physical access is a barrier, as well as gaps in support. As in many areas of life, disabled people may experience inappropriate attitudes and the use of health and safety regulations to exclude them. Shockingly, there are also instances of hate crime being perpetrated against them.

'I went from volunteer to paid staff member'

Tom Sutcliffe, from Edinburgh, is the marketing manager for a small charity

"I was a volunteer for two years at the charity where I am now employed. When the founder of the trust found out he had terminal cancer, he left a legacy to employ someone to do his job [after his death].

After gaining a master's degree, I went for various jobs without success, even though I had management skills from employing Personal Assistants. I then applied for this job and got it; I now work 12 hours a week. It's busy, but I enjoy it.

I have control over what care I get and when I get it. I have cerebral palsy and use a manual wheelchair. On my journey to work, I can get to the bus, but, when I get off, there's a huge junction I need help with.

In 2004, I bought my own flat. I have lots of friends and a good social life. I have people in throughout the day to help me live the life I want. For instance, I can cook for myself, but it's a question of time.

As a user of Direct Payments, I get very frustrated by the legal stuff and paperwork. When I moved to Scotland from England, my new local authority refused to fund me, and my previous local authority threatened to stop my Direct Payments. I went ballistic, but I fought my corner. It was stressful, though – other people might not be in a position to do that.



And action!

Here's what needs to happen...

Disabled people are calling for urgent changes relating to economic, social and public life, which mirror those in other areas, including:

the enforcement of legislation and policy; the identification of new developments; involvement of disabled people in all relevant bodies and developments; key strategic documents to be consistent with promoting independent living; disability-equality training for relevant staff; and identification of issues for all disabled people.

And, more specifically...

To tackle these issues, there must be national development to support the employment of disabled people. For inclusion to be achieved, initiatives, such as Access To Work schemes, must be promoted. When someone acquires an impairment, or an existing impairment worsens, barriers to keeping their job must be reduced.

There also needs to be improved information and support; development of national and local opportunities for work experience; along with opportunities for training, participation and volunteering. Protection from harassment must be stepped up, and reporting, prosecution and monitoring of hate crime improved.



The bigger picture

Scotland needs an overall political, social and service structure that will embrace and promote independent living

How it should be:

Independent living at every level.

How it is:

There is still a long, long way to go. A strategic and holistic approach to independent living remains to be achieved in some policies, legislation and services. There is limited inclusion of disabled people in policy making; and the specific requirements of particular groups are not always recognised. Inappropriate attitudes from service providers and other community members continue to erode the independent living ethos; and there are gaps in disability-equality training. At present, there are too few resources to support independent living, and existing resources are not being used appropriately. Despite supporting evidence, there is a lack of focus on the economic benefits of independent living.

‘Thus shall we live, because we will have created a society which recognises that all people are born equal, with each entitled in equal measure to life, liberty, prosperity, human rights and good governance.’

Nelson Mandela,

Nobel Peace Prize Acceptance Address,
10 December 1993

'Cost-cutting is restricting my son's independence'

Maire McCormack, from Linlithgow, talks about the issues facing her son Matteo, 16



I always wanted Matteo to be taught in a mainstream setting – he is profoundly deaf and has mild Asperger's – but, as I got to know the deaf community, I realised it would be more inclusive for him to be taught with other deaf children.

Socially, Matteo is keen to be part of the community. He goes to the local youth club, who are desperate to be accommodating. But, when they go away, he can't go. Last week, he wanted to go climbing, but safety was brought up as an issue. I mean, he's deaf!

His choice is completely restricted. There is a lack of British Sign Language interpreters – it's a cost issue. There was an event Matteo wanted to go to, so I provided the signing. But he's 16 and doesn't want to be with his mum all the time.

A buddy scheme would benefit Matteo. He needs to be with people his own age outside school – deaf or hearing. He's reaching transition stage and is just not prepared. There used to be similar schemes, but funding was withdrawn.

Scotland has reasonably good legislation in theory. There are lots of good policies, but, in practice, councils are just cost-cutting.

And action!

Here's what needs to happen...

Disabled people are calling for urgent changes relating to Scotland's overall political, social and service structure, including:

implementing, reviewing and developing legislation and joined-up policy; greater involvement of disabled people; developing and delivering services consistent with the principles of independent living; appropriate attitudes from staff and the public; and consideration of issues for all disabled people.

And, more specifically...

Scotland desperately needs an independent-living strategy and vision. National and local structures must be developed, as must links to promote independent living, such as local partnerships and inclusion of disabled people on specific groups. Legislation, policies and services should be compatible with the principles and practices of independent living, and training must be made available to promote shared understanding and good practice for policy makers and practitioners alike. But that's not all. More capacity must be built in national and local organisations run by disabled people for disabled people, and attitudes towards disabled people must be addressed. The costs and benefits of independent living in Scotland should also be identified, showing how independent living is an investment, with the provision of appropriate funding.



The whole story

'I need a suitable home and more support'

Lack of independent living doesn't just affect one aspect of your life, as Pauline Peat, from Edinburgh, knows only too well

"I live in a three-bed semi, and, now my sons have left home, I have little assistance. I have hand rails and seats here, there and everywhere, including the bathroom, but I don't have a shower that often – that is paid for in pain and exhaustion, because I have a degenerative spine disease.

I need a home suited to my needs and more support. I used to have a housing-support officer; not any more. I also had home help; that was taken away. I was told to get my family to do it!

Now, the mortgage company has started legal proceedings for repossession. The council has little to offer in the way of suitable accommodation, and, the homes I've applied for, I've not got. I've also been on the waiting list for more support from a charitable organisation for a few years."



Daily struggle

"I don't feel that I have independent living at all, really, although I force myself to do things, like regular voluntary work to help deaf and hard-of-hearing people, like me. I earned a volunteering award from the council for that.

For many years, I worked in tax and accounting, but my spine got too bad for me to work. I had already started doing counselling courses, but so far have not been able to finish those, due to ill health.

Getting Disability Living Allowance (DLA) has provided an adapted car to take me and my old wheelchair places, but that means I can't use DLA to get a new wheelchair with electric tilt that I need, as well.

Taxis are expensive, and I have trouble fitting my large wheelchair up the ramps. I have crashed to the ground a few times. Mind you, I managed to topple sideways off my own car ramp at hospital one day. Just as well I was in the right place for medical assistance!

If I could get the right house, support and wheelchair, maybe I could finish my counselling qualifications and get a job, counselling part time."

This cannot go on...

Freedom. Choice. Dignity. Control.

The time to make these a reality is now

The Independent Living in Scotland (ILiS) project provides the perfect opportunity to strengthen the independent living movement and to promote independent living in Scotland. As this leaflet reveals, many issues must be tackled. From service providers working better together to more employment support. Disabled people have highlighted the areas that are absolutely crucial to enabling choice, control and freedom, and these priorities will help to inform the work of the ILiS project. The achievement of independent living would change many people's lives in Scotland.

'The more people understand the more they can get involved, the more they can get involved the more they can do, the more they can do the more people listen, the more people listen the more attitudes change.'

Steven Robertson,
People First Scotland



The achievement of independent living would change many people's lives in Scotland.

Independent Living in Scotland

Inspire. Involve. Invest.

Inspire

Inspiring all disabled people and the Independent Living Movement plus politicians, policy makers, service communities and organisations.

Involve

Involving all disabled people in developing the policies and services that impact on them.

Invest

Investing in the Independent Living Movement, and in people, communities and services to make a better society for everyone in Scotland.

That's our goal.

Information

For more information about this project, visit www.ilis.co.uk.

Independent Living in Scotland Project
Equality and Human Rights Commission
Optima Building, 58 Robertson Street
Glasgow, G28 DU

Telephone: 0141 228 5921

You can contact the Equality and Human Rights Commission via our website at:
www.equalityhumanrights.com

or by contacting the helpline.

Helpline – Scotland

Telephone: 0845 604 5510

Textphone: 0845 604 5520

Fax: 0845 604 5530

9am – 5pm Monday to Friday,
except Wednesday 9am – 8pm

**Equality and
Human Rights
Commission**

equalityhumanrights.com