

Case study 148

What Works in Tackling Poverty

Independent Living in Scotland

What are case studies?

Case studies share what people and organisations have learned from delivering or developing a project or programme. They can help you to see what has worked on the ground and can give you ideas about how to tackle problems. They can also signpost you to people and organisations you may want to talk to.

Independent Living in Scotland

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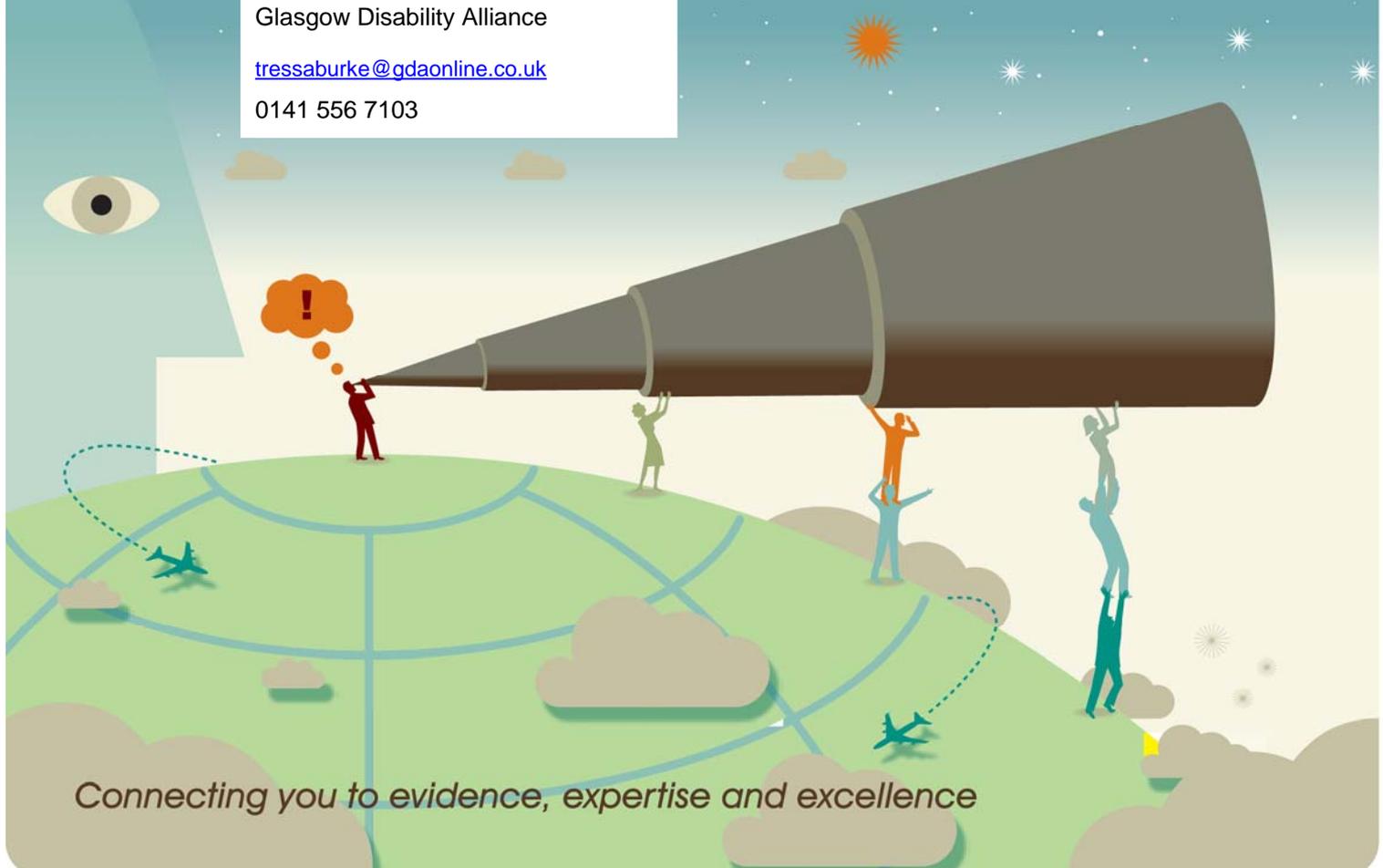
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In a nutshell

The connection between poverty and disability is complex and multi-directional. Disabled people face many barriers to full participation in society, including; discriminatory attitudes, isolation as a result of inadequate housing and transportation, restricted access to learning, education, work, health services, community facilities, lack of communication support and opportunities to participate in decision making. This perpetuates the myth that disabled people are benefactors of, not contributors to, society and it means disabled people are likely to face an increased risk of social exclusion which is a major contributor to the high levels of poverty they experience.



Connecting you to evidence, expertise and excellence

Independent Living, a shared vision of the Scottish Government, COSLA, the NHS and the Independent Living in Scotland (ILiS) Steering Group, is based on the core principles of **dignity, freedom, choice, and control**. It's about disabled people having equality of opportunity at home and work, in education and in the social and civic life of the community.

The issues

Facts and Figures about Disability ¹

- Scotland has over one million disabled adults, this includes:
 - 1 in 4 people who experience a mental health problem
 - 758,000 people who are deaf or hard of hearing (5-6,000 are first language BSL users)
 - 36,000 people who are registered blind or partially sighted
 - 5,000 people who have dual sensory impairments
 - 120,000 people who have a learning difficulty
 - Figures also indicate that there were 96,000 wheelchair users in Scotland in 2006, yet only 5,800 wheelchair adapted houses. (There is an estimated need for an additional 230,000 properties suitable for disabled people and their families)
 - 42% of households with one or more disabled people have an annual income of less than £10,000. This compares with 26% for households with no disabled person
 - When the extra costs of being disabled are taken into account, 47.5% of families with disabled people in the household, live in poverty ²
 - Disabled people are twice as likely as others to have no recognised qualifications
 - The rate of unemployment amongst disabled graduates is 14% higher than that for non-disabled adults with no qualifications at all

- Young disabled people aged 16 are twice as likely not to be in any form of education, employment or training (NEET) as their non-disabled peers – this increases to three times as likely by the age of 19
- By the age of 26, young disabled people are more than three times as likely as other young people to agree with the statement “whatever I do has no real effect on what happens to me”
- 52% of disabled people are unemployed
- Disabled adults are now more likely to live in poverty than either pensioners or children
- Of all children living in poverty, one in three has a disabled parent
- It is estimated that in 2004/5, 40% of households in the UK experiencing fuel poverty contained a disabled person
- Disabled people in work are more likely to be in low paid, low skilled jobs
- 50% of disabled people do not receive the appropriate disability living allowance
- Disabled people in the UK are twice as likely to be in persistent poverty (defined as living at 60% of median income for 3 out of 4 years) as non-disabled people at 11% and 5% respectively
- Pensioner poverty continues to be greatest among older and female pensioners, disabled pensioners not in receipt of disability benefits and ethnic minorities
- People who are disabled officially constitute only 6% of formal volunteers and around 4.3% of public appointments across Britain. This is compared to 20% of the population at large.

Independent Living in Scotland

As a disabled person, the right to have control over their life is more often than not denied. The definition of independent living, developed by disabled people, and adopted by the Independent Living in Scotland project is:

¹ Glasgow Disability Alliance; Rights to Reality: Charter of Rights for Independent Living; Manifesto for General Election 2010

² “Destination Unknown”; Demos report, 2010



“Independent living means disabled people of all ages having the same **dignity, freedom, choice, 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”

The principles of independent living, i.e. **dignity, freedom, choice, and control**, do not only relate to the specific services and provisions for disabled people, but to the whole of disabled people’s interactions with society; its organizations, facilities and structures; and every aspect of their quality and equality of life.³ For independent living to be the reality, disabled people need access to the following basic rights:

- Full access to our environment
- Fully accessible transport
- Technical aids and equipment
- Accessible and adapted housing
- Personal assistance
- Inclusive education, training and lifelong learning
- An adequate 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
- Opportunities for social and civic participation
- Counselling and peer support, including peer counselling
- Accessible and inclusive health care
- Communication and appropriate support for communication.

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

One of the approaches to the issues

Self-Directed Support

For some disabled people, independent living requires adequate and empowering personal support. Health and support services – not ‘social care’ – that meet disabled peoples’ needs, enabling choice and control. Self

Directed Support is one way to do this. The underlying principle of self-directed support is the development of a culture and the tools to enable people to take greater control of their lives and the support they receive, so that they can make the decisions and manage their own risks. This puts people at the centre of assessing their own needs and tailoring support to meet their needs.

Direct payments and individualised budgets give people who use social care the opportunity to control the resources allocated to their support.

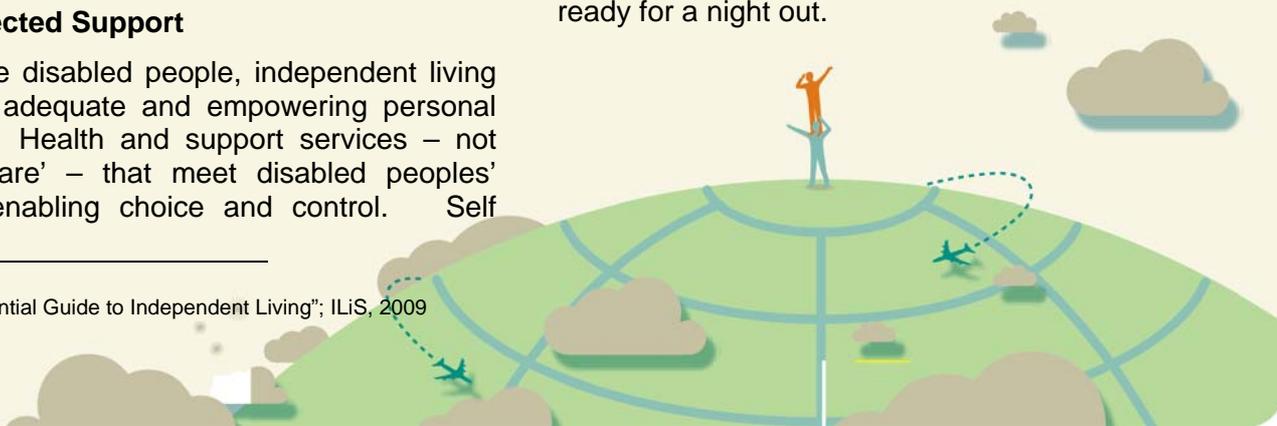
Direct Payments and Individual Budgets

Direct payments enable people to have cash instead of services and use it to meet their support needs. Direct payments can be used in a variety of ways, such as buying special equipment, spending time away from home, going to a gym, eating out, employing a personal assistant to help with everyday tasks and so on. An Individual budget is a single transparent sum allocated to a person in their name and held on their behalf rather like a bank account. They can choose to take this money out either in the form of a direct payment in cash, as provision of services, or as a mixture of both. Resources from different agencies, not just ‘social care’ monies, can be collated together and accessed from the one individual budget to give the individual a more joined-up package of support.

Pam’s Story – a journey to self-directing support

Pam left home at 18, moving 150 miles away to study at university. Going to university didn’t just mean meeting new friends and starting a new career however, it meant that she was going to have to rely on community care for the first time instead of her parents who had always provided her care. This meant people she had never met before supporting her to get out of bed, use the toilet, get dressed, cook, get to university or get ready for a night out.

³ “The Essential Guide to Independent Living”; ILiS, 2009



Using community care for the first time was not an easy experience but one she had to familiarise herself with quickly. She found that she had to justify not wanting a 'bed-down' at 9pm or why she needed support *all day* for toilet access as opposed to having to intrusively monitor her liquid intake and output to gauge toilet breaks. It took a lot of perseverance and convincing to finally get a needs assessment that reflected the fact she was an 18-year-old woman. In the end she wrote and costed her own care plan that reflected her needs and allowed her to fully participate in society.

After a two year struggle, Pam had an excellent support package that allowed her to do all things community care *should* - eat, sleep, get washed, but *also* study, work voluntary part time in the disability rights movement, be a disability activist, get involved with a political party and stand as an MSP candidate, go out with peers and socialize. Pam gained an Honours degree in psychology and an MSc in Health Psychology. She started working for the Glasgow Centre for Inclusive Living for 4 years before moving on to take up a post with the Equality and Human Rights Commission as Policy Officer for the Independent Living in Scotland Project.

Without good, flexible community care, Pam's story would be very different. If it were not for the flexible support of a personal assistant, she would not have been able to lead such an active and diverse life; her social life and involvement in the community would have been limited, her education would have suffered which in all would have restricted her employment prospects. Essentially, her quality of life would have been diminished which could have affected her mental well being and impacted on her physical health, both of which are more of a strain on the NHS.

Pam believes that such community involvement and active citizenship helps this country build a healthy attitude to diversity and ensures it draws on skills it would otherwise have shut out.

Challenges

1. The delivery of Self-Directed Support has become a postcode lottery - where you live and what you know is a pre-requisite in determining the provision of care

2. The systems in place to promote direct payments and individual budgets can be bewildering. Advice on how to use them is sporadic with many professionals themselves not fully understanding the underlying principles
3. Budget cuts has had a further impact on the money available to implement and promote delivery
4. Whether receiving benefit entitlement or in employment, disabled people are liable to pay for some of their own community care. The extent is dependent on the local authority and individual circumstances. For someone like Pam who is working and needs support for a lot of hours in the week to meet her needs, in some LA's, she would need to earn in excess of £50,000 a year before ever being able to keep more than the equivalent of income support. This is a disincentive for many disabled people to work at all, take on full time hours or accept a promotion and is a barrier to full, active and inclusive participation.

Glasgow Disability Alliance

Glasgow Disability Alliance (GDA) is a robust and growing disabled people's organisation (DPO) with over 1000 disabled members (March 2011). As well as disabled individuals, GDA has 38 organisational members, meaning their reach is far wider. GDA is committed to challenging discrimination and building the skills and confidence of disabled citizens so that they are empowered to have ***dignity, freedom, choice*** and ***control*** over their own lives.

Members Concerns about Poverty

GDA members are currently concerned that the limited progress on rights and opportunities has stalled. Moreover, that progress may be lost as austerity measures are used to cut services despite the unequal and hugely negative impact on the lives of disabled people.



This problem arises in relation to reserved issues e.g. welfare benefit reform and devolved matters e.g. education, learning, health and housing. There is still a problem in the public sector understanding that in order to achieve equality, there needs to be positive action:

“Poverty limits my choices on top of lack of access. Its layers and layers of problems from my house, to not having transport to the fact that I cannot take part in jury service as there’s no communication support which I need as I have a hearing impairment” GDA Member.

GDA’s Approach to these Concerns

GDA works in partnership as part of the Independent Living Movement in Glasgow and Scotland, providing advice, information, training and consultancy for organisations and agencies. GDA shares disabled people’s experiences and supports the engagement of disabled citizens. GDA has been pleased to receive funding to run three separate projects which have been set up to address unmet needs:

Learning for Change

Funded by the Big Lottery, this project provides a range of accessible lifelong learning courses so that disabled people can build confidence and skills and reach their full potential. An evaluation showed the longer term impact of GDA’s work:

*“Increased confidence and self esteem and consequently improved motivation and increased access to further learning and wider civic opportunities...”*⁴

Rights to Reality

Funded by Equality & Human Rights Commission this aims to give young disabled people and their families more information, advice, learning, peer support and opportunities to develop self-advocacy and achieve choice and control in their lives. Wider aims including sharing learning with agencies to improve services for young disabled people.

Disability Equality Programme

Funded by Glasgow City Council aims to empower both disabled people and public agencies through the provision of accessible information, advice, learning, peer support and capacity building. Disabled people are enabled to secure rights and obtain access to services, thus having more choices and greater control over their lives. The project also aims to improve policies and services for disabled people.

Evidence of success

GDA’s priority has been to transform services so that disabled people achieve choice, control, dignity, freedom and a fair and equal chance at living a full life.

GDA has done this by working in partnership with service providers, representing the key issues and priorities of disabled people. At the same time, GDA has enabled disabled people to develop the skills and confidence to become a powerful voice by providing training, support and building capacity.

A key outcome has been the friendships and support networks that have grown up between disabled people, their groups and their wider social contacts which have enabled individuals and the disabled peoples’ movement in Glasgow to become more effective.

GDA supports and encourages disabled people to develop their own voices to become citizen leaders. One member pointed out:

*“It’s impossible to choose what you want to do and when you want to do it when you can’t access transport and have no personal assistance. You also need information about your rights and GDA have been critical in telling us about these and giving us access to learning to make sure that we have the knowledge and confidence to use our voices...”*⁵

⁴ PZA, External Evaluation 2010.

⁵ GDA Campaign Action Group Member in Annual Review 2008-9



GDA has deliberately invested time and expertise in making contact with disabled people, many of whom have never joined or been an active member of an organisation before. An external evaluation of GDA highlighted this success:

“The out performance of targets reflects the exceptional levels of promotional activity that GDA has carried out in order to access disabled people from across the city and other equalities networks...”⁶

Manifesto for Action on Independent Living

GDA have found from members that too often disabled peoples' lives are blighted by poverty and discrimination, e.g. community care charges plunge disabled people further into poverty and create work disincentives: *“I had a real decision to make about whether it was worth my while working as the community care charges are so high. Other people get to keep their wages but disabled people using community care services have to pay charges and the amount all depends on where we stay. We are the only folk who are paying increasing taxes in Scotland. It is not fair and it is not justice,”* GDA Member, January 2011

GDA have launched a Manifesto for the Scottish Parliament elections on May 5 2011, calling for action to address this. Specifically this asks MSPs to respect and support human rights and promote civic and social participation by taking action on:

- Personal Assistance & community care charges
- Inclusive lifelong learning and education
- Accessible information & communication
- Accessible housing, transport and healthcare.

For more information see

www.gdaonline.co.uk

⁶ PZA, External Evaluation 2010



Scottish Centre for Regeneration

This document is published by the Scottish Centre for Regeneration, which is part of the Scottish Government. We support our public, private and voluntary sector delivery partners to become more effective at:

- regenerating communities and tackling poverty
- developing more successful town centres and local high streets
- creating and managing mixed and sustainable communities
- making housing more energy efficient
- managing housing more efficiently and effectively

We do this through:

- coordinating learning networks which bring people together to identify the challenges they face and to support them to tackle these through events, networking and capacity building programmes
- identifying and sharing innovation and practice through publishing documents detailing examples of projects and programmes and highlighting lessons learned
- developing partnerships with key players in the housing and regeneration sector to ensure that our activities meet their needs and support their work

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The views expressed in case studies are not necessarily shared by the Scottish Government. March 2011