Capability Scotland campaigns with, and provides education, employment and care services to disabled people across Scotland.

Introduction

Capability Scotland welcomes the opportunity to respond to the Equal Opportunities Committee’s inquiry on age and social isolation. Many of our services, particularly community living, local area co-ordination, early-years and short-break services are committed to relieving the social isolation faced by disabled people and families of disabled children across Scotland.

While the focus of the committee’s inquiry is to explore the issue from the perspective of age (specifically in relation to both younger and older people), it is vitally important to recognise that social isolation affects disabled people of all ages and backgrounds. We therefore believe that social isolation should be considered in relation to the full range of protected characteristics specified in the Equality Act 2010.

Initial Feedback

This point has recently been reinforced through consultation with our customers and supporters, many of whom have reported to us that age is irrelevant when it comes to the isolating effect of the social barriers experienced by many disabled people and their carers across Scotland. A 50 year old customer from our Upper Springland service in Perth said to us:

‘My age has nothing to do with my isolation, in my case my speech isolates me as people cannot easily understand me and they are put off from speaking to me. My care package doesn’t include speech and language therapy so my speech hasn’t improved since a cerebral bleed 3 years ago. I moved house to reduce my isolation but difficulties with communication have prevented me from making friends locally. This makes me feel very lonely at times’

An advice service customer (who is in her 40s) explained to us that access issues and a lack of support compound her social isolation following a diagnosis of MS;

‘People don't know how to push a wheelchair and collapse it and put into their cars so they end up visiting rather than take me out.. I live alone and have no support. I can't wheel the chair myself due to my MS. I can't go anywhere by myself and need help to do this. People say 'use the taxi service' but when I tried this it was very awkward and they were reluctant to wheel me out of my home and help me lock my door - they expect you to have someone with you. I'm also isolated once I reach my destination as I am by myself and can't go anywhere. I can't go to an opticians, dentist, GP, shops etc because I have no-one to help me do these things and I don't know how to access them. Even going to see a consultant at the hospital is a
nightmare for me! I have to stay home as I have no choice and am therefore forced to be isolated"

The terms social isolation and loneliness are often used interchangeably in this consultation. In responding to the inquiry however, Capability Scotland is of the view that they are distinct, with isolation a measure of the social contacts that people have, and loneliness categorised as a subjective negative feeling which very often accompanies it. The important implication of this distinction is that someone can have a large number of connections and still feel lonely, or alternatively, be isolated in an objective sense but not necessarily experience associated negative emotions.

A support worker at our Sycamore Service for children on the Autism Spectrum explained ‘Many of the young people who use our service are isolated at home when not with us or at school, this puts enormous pressure on their parents and other siblings - but they are not all lonely. They are often attending school irregularly or are having problems at school and so their age-appropriate friendship groups are small or non-existent. Some of the children are adversely affected by this in terms of how they feel but not every child is, it’s very individual’

Many parents of disabled children report to us that post-diagnosis of their disabled child they might be surrounded by well-meaning and caring friends or relatives but feel very alone. As one advice service customer explains:

‘When my daughter was diagnosed with cerebral palsy we felt so alone and isolated – we didn’t know where to go for information and advice and we didn’t know anybody else in the same situation. I was so stressed and depressed about our future, I really felt exhausted by all the medical advice we received but there were no other services to support us emotionally as a family’

Barriers to participation

Disabled people, those living with long term conditions, unpaid carers and parents of disabled children face multiple barriers to participation which can contribute to their experience of loneliness. These can include:

- Poverty and low-incomes
- Having to give up paid work
- Poor physical access to transport and the built environment
- A lack of information and advice about services that would allow positive social interaction
- A lack of suitable childcare
- Poor information and support after diagnosis of a disability
- Difficulties accessing therapy services that would help to ease barriers to socialising such as communication and mobility impairments
- Poor access to transport
- Stigma and discrimination
Recent research by Sense has found that in a survey of 1,004 disabled adults across the UK 23% feel lonely most days, rising to 38% for young disabled people. Some 29% reported only being able to meet up with friends once a month or less, while 6% said they had no friends at all. More than four in 10 disabled people said that being able to live more independently would allow them to see their friends more often. And 22% said an improvement in accessible public transport would make it easier to leave the home and socialise with friends.

In addition to this, research conducted by Contact a Family (2011) revealed that 70% of families with disabled children have experienced anxiety, depression, isolation or family breakdown as a result of social isolation. 51% felt so unwell they have asked their GP for medication or have seen a counsellor, 64% felt most isolated when their child was first diagnosed. Over half (56%) said their feelings of isolation were due to a lack of support from social services and the education system, while 57% believed it was because they could not work as much as they wanted to and 54% blamed a lack of time and money.

Through our work to support families with disabled children we see that they experience social isolation in different ways:

- a lack of social interaction due to difficulties working and not having the time or money to do family activities others take for granted
- a fear of how people will react when they go out with their disabled child
- a feeling of being alone, even when they are surrounded by people, because no one else shares their experience.

The experience of our advice service which offers support to parents from the earliest stage following diagnosis suggests that isolation can have a devastating impact on the mental health of many families with disabled children. As a parent of a child with a recent diagnosis of Angelman syndrome told us:

‘We were so depressed when we got the diagnosis, both my partner and I, our outlook on life was suddenly so bleak because we were getting so much information about what our daughter wouldn’t be able to do and nothing really positive at all. It was such a dark time I wouldn’t wish it on anyone. Without support from Capability Scotland early years service and the opportunity to informally meet other parents of disabled children I don’t know what we would have done’

Prevalence of social isolation in rural settings

Transport is a key issue for disabled people, particularly those in rural Scotland. Customers at our Dumfries and Galloway service frequently report that they are often 'trapped' in their own homes by limited public transport options and the high cost of transport when it is available. As one customer told us:

‘My wheelchair is too big to get on the local buses and I struggle to get taxis or private hire cars that I can afford or who will agree to take me and who won’t charge me extra for carrying

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1 TFN News13th March 2015: Disabled facing increasing loneliness and isolation
the chair. This is a major problem in terms of getting out to see friends and family and I find that weeks have gone past without me having left the house’.

In rural areas of Scotland it can be very difficult to reach services or other places by public transport and prohibitively expensive if disabled people don’t use cars or can’t use buses. Over half of the residents of rural Scotland in 2009-10 reported having to spend over £100 a month on fuel for cars, compared to 38% in the rest of Scotland. Given that a third of families with a disabled child live on less than £15,000 a year in Scotland these types of cost can be prohibitive to those in rural areas.

If social isolation in rural areas for disabled people is to be addressed there needs to be a strong commitment from relevant agencies to creating an accessible affordable transport system for all. The ability to move around the community underpins all aspects of life, however for disabled people, access to transport, whether public or private, can be a lifeline, opening doors to employment and socialising opportunities, making independent living possible and radically impacting on quality of life.

Despite a number of improvements over the past decade, including the obligations placed on transport providers by the Equality Act 2010 and technological innovations, disabled people still face many barriers preventing them from getting access to transport services. As well as the more obvious physical barriers there are also attitudinal and psychological barriers such as a lack of understanding by staff, fear of crime or abuse, the way information is communicated, availability of particular types of services needed by disabled people as well as affordability.

Governments and transport providers need to ensure accessibility for disabled people is a condition of public investment, licensing and franchising (as well as other procurement and subcontracting), reinforced by regular reporting so that all statutory requirements under the Equality Act 2010 are met. As a founding member of Disability Agenda Scotland, Capability Scotland supports the call for:

- Ensuring information is available in a range of formats including the latest technology is available for all publicly licenced transport services to enable disabled people to easily plan and make their journeys
- Ensuring disabled people and organisations are meaningfully included in the planning, design and operation of transport services, facilities and operations from the beginning
- Ensuring help with travel costs and monitoring welfare changes to ensure disabled people’s mobility is not impaired by unjustified additional expenditure
- Continuing to work with British Transport Police and Police Scotland to address safety and security concerns, including hate crime, of disabled travellers on public transport

There is evidence to suggest that the isolation of remote and rural communities may produce a culture of self-reliance and stoicism from disabled people towards problems such as social isolation. Research specific to Scotland has found that although there are many cultural traits

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3 Contact a Family Counting the Costs 2014
4 Disability Agenda Scotland, Our Vision for an Equal Future; Manifesto for 2015 General Election, 2015
that are common to both rural and urban areas, culture can vary between urban and rural communities, and even across rural communities\textsuperscript{5}. Physical isolation from social networks and support services, combined with an exaggerated culture of self-reliance, is thought to contribute to stress, anxiety and depression for disabled people in rural areas. Scottish research has shown that higher visibility in small communities can prevent some disabled people from seeking support for mental ill-health, and cause them to ‘hide' problems from the rest of the community\textsuperscript{6}.

**Access to services in rural areas**

Access to healthcare should be as local as possible, for everyone in Scotland, no matter where they live. However, in Scotland, the experience of healthcare for people in rural areas differs from that of people in urban areas in that they often have to travel large distances to receive care\textsuperscript{7}. Remote rural areas are the only areas in Scotland which are not within a 15 minute drive time to key services. For example, 93% of people in remote rural areas live within a 15 minute drive time to a GP compared to 100% of the population of accessible rural areas and of the rest of Scotland. One report has said that hospitals, mental health care and GP provision are all currently being reduced at a local level, with services being centralised in main towns and community services withdrawn\textsuperscript{8}.

**Policy solutions to social isolation**

The solutions which are likely to be most effective and sustainable in addressing social isolation of disabled people are likely to be those shaped and driven by disabled people and communities themselves. The challenge is to spread and sustain these examples of good practice in a way which adapts to different local contexts rather than spreading a one-size-fits-all model in a top-down approach.

Connecting disabled people to local support options as well as identifying and sharing knowledge of community resources, can go some way towards reducing social isolation. This can include low-level intervention that gets a useful job done but that provides disabled people with social contact, for example assisted uplift for rubbish collection or handyman services for jobs around the house. When asked what services would reduce a sense of social isolation, a customer of Capability Scotland’s advice service told us;

‘I can't understand why there is no service 'run by vetted volunteers' to do ‘wee tasks' for disabled people like getting milk and bread, a newspaper, getting a birthday card, posting letters, putting rubbish into bins etc - that kind of 'simple' support would be a great help’

Despite the potential benefit to both people and statutory services, signposting from the NHS to the third sector remains patchy and there are opportunities to enhance access to local information.

\textsuperscript{5} Scottish Executive, Poverty and Social Exclusion in Rural Scotland. (2001)
\textsuperscript{6} Scottish Executive, Poverty and Social Exclusion in Rural Scotland. (2001) cited in
\textsuperscript{8} Voices of Women in Rural Scotland, Scottish Women's Convention, 2012
Our [Local Area Co-ordination Service](#) in East Lothian helps to signpost and support disabled people to access useful community support such as places, groups, activities, opportunities, events and services. The LAC service model is a good practice example of how to connect socially isolated disabled people and their local community. As our co-ordinators explain this service can act as a lifeline to disabled people who once felt isolated:

‘Many of our customers come to us when they are at a very low ebb in terms of their contact with the outside world. Learning disability or access problems due to mobility and other impairments may mean they were at home a lot more than other people and dependent on paid support workers for social interaction – something that can be stilted and strained at times particularly if people are not satisfied with their own care package. Our service links them to social activities where they can really be themselves and open up to others – this is crucial to tackling the problems of social isolation like depression and poor physical health. It really contributes to health and wellbeing’.

Conclusion

The Committee’s inquiry coincides with the ongoing Community Empowerment Bill, the integration of health and social care and the implementation of the Public Bodies (Joint Working) (Scotland) Act 2014. The principles underpinning planning and delivering integrated health and social care included in the Act, and subsequent guidance, highlight the importance of support for participation at a local level, full citizenship and connectedness.

Given the established links between disability, long term conditions and social isolation, Capability Scotland encourages the Committee to engage with disabled people directly, third sector organisations as well as Health and Social Care Partnerships on how local implementation of integration is seeking to tackle social isolation.

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