

Independent Living in Scotland

1. Introduction

Please also see ILiS and Inclusion Scotland's previous consultation responses to the Finance Committee's call for evidence on the budget and various submissions on the Public Bodies Joint Working Bill.

- 1.1 The Independent Living in Scotland (ILiS www.ilis.co.uk) project aims to support disabled people in Scotland to have their voices heard and to build the disabled people's Independent Living Movement (ILM). It is funded by the Scottish Government Equality Unit to make the strategic interventions that will help to make independent living the reality for disabled people in Scotland and hosted by Inclusion Scotland.
- 1.2 Inclusion Scotland (IS) is a Scottish-wide consortium of self-organised groups of disabled people and disabled individuals. Currently over 60 organisations of disabled people and over fifty individual disabled people are members. Inclusion Scotland's main aim is to draw attention to the physical, social, economic, cultural and attitudinal barriers that affect disabled people's everyday lives in Scotland and to encourage a wider understanding of those issues throughout Scotland.
- 1.3 Disabled Peoples Organisations (DPO's) are organisations led by and for disabled people. You can find out more about them in the ILiS publication "It's Our World Too", available at www.ilis.co.uk.
- 1.4 Both ILiS and Inclusion Scotland are part of a wider Independent Living Programme in Scotland. This programme seeks to make independent living a reality for disabled people in Scotland¹.
- 1.5 **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**" (definition developed by disabled people, adopted by the partners in the Independent Living Programme – the NHS, The Scottish Government and COSLA, and set out the vision for independent living).
- 1.6 For many disabled people, this practical assistance and support (such as access to the environment, advocacy, personal assistance, income, and equal opportunities for employment), underpinned by the principles of independent living, **freedom, choice, dignity and control**, is essential for them to "flourish"; to exercise their rights and duties of citizenship, via their full and equal participation in the civic and economic life of Scotland.
- 1.7 The role independent living plays in protecting the human rights of disabled people in this way, is recognised and underpinned by international human

¹ <http://www.scotland.gov.uk/Publications/2013/04/8699>

rights and equalities obligations to which the UK and Scotland are party to; including the recognition that all of the rights outlined in the European Convention on Human Rights (ECHR) and Human Rights legislation belong to disabled people, and that these are further strengthened and contextualised by the rights set out in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

2. Health inequalities

2.1 One in 5 people in Scotland are disabled i.e. people with physical, sensory, learning or psychiatric impairments or other long-term health conditions and they make up over a third of NHS users. While many disabled people receive an excellent service from the NHS, large numbers still experience significant health inequalities in Scotland:

- only 39% of disabled people, compared to 92% of non-disabled people, say they are in good health
- disabled people have poorer mental health than non-disabled people
- disabled people have poorer dental health than non-disabled people²
- people with learning disabilities live 20 years less on average than the general population³

3. Reasons for the health inequalities faced by disabled people

3.1 Disabled people themselves are more likely to live in poverty and so the inequalities in health are the result of both social deprivation and of being disabled.

3.2 People with visual impairments are communicated with in inaccessible formats (i.e. via typed letters when they have specifically requested braille or e-mails). One example we are aware of is of a visually impaired (blind) woman who fought a Health Board for 2 years to get letters and appointment notification sent by e-mail even though the Equalities & Communication Policies of the same Board stated that patients had the right to be communicated with in an accessible form. The excuse for not communicating by e-mail was Data Protection which the Board claimed over-rode Equalities considerations.

3.3 For many disabled people, social care is an essential part of ensuring disabled people can enjoy the same human rights as non-disabled people. It is also a crucial part of preventing admissions to hospital. However, with significant levels of unmet needs within the Social Care system⁴ and rising charges for it (further impoverishing disabled people); preventative measures are not being used and social deprivation is compounded⁵.

² Scottish Health Survey; 2012

³ Scottish Government; "the Key to Life: learning disability strategy"; 2013

⁴ <http://www.ageuk.org.uk/professional-resources-home/public-affairs/reportage/past-issues-of-reportage/reportage-february-2012/viewpoint-is-there-a-gap-in-social-care-funding/>

⁵ <http://www.scope.org.uk/news/massive-economic-benefits-providing-social-care-disabled-people>

- 3.4 Social isolation leads to more deaths in Scotland per year than cancer and heart disease combined, yet vast numbers of disabled people remain isolated in their own homes. This isolation is the consequence of various factors, including; that social care provision rarely takes account of social participation (given rising eligibility criteria and high levels of unmet need), poverty, increased hate crime and hostility towards disabled people making them afraid to go out, and, the fact that many disabled people are living in a house that they cannot get in and out of.
- 3.5 People with a mental health problem or learning disability face difficulties when trying to use the service provided by their health centre or doctor's surgery. A small number have even reported not being registered or being struck off a GP's list, for instance, for being 'too demanding'.
- 3.6 Disabled people surveyed on their experience of treatment within the NHS stated that as disabled people, they experienced a lack of sensitivity and understanding of their health care needs from all areas of the health service from primary through to acute care.
- 3.7 People with mobility impairments, and indeed anyone on a low income, have huge difficulties in accessing health services because of the retreat of ambulance services into solely "emergency" work and the complete inadequacy of public transport in filling the gap, particularly in remote and rural areas.
- 3.8 This leaves disabled people and those on low incomes unable to access out of hours treatment unless they have taxi fares or being improperly discharged when they have no means of getting home:
- Around a fifth of disabled people report having difficulties related to their impairment or disability in accessing transport⁶;
 - around a third of disabled people experience difficulties related to their impairment in accessing public, commercial and leisure goods and services⁷;
 - in remote rural areas, over two thirds (70%) of those aged 60 or over either do not have a free bus pass or do not use it, this contrasts with less than a third (31%) of older people in large urban areas – the figures are likely to be similar for disabled people entitled to the National Concessionary Transport scheme;
 - overall, there is less travel by bus in rural Scotland and residents in the countryside are less happy with public travel services than their counterparts in urban places;
 - people in rural areas make fewer journeys by bus to access health services than those in urban areas, and are more likely to drive or travel

⁶ ONS OpinionsSurvey 2011

⁷ ONS Opinionsurvey 2010

as a passenger (for example in taxis or being transported by a family member) to medical appointments. However, given the large numbers who may lose their Motability vehicles (an estimated 16,000) after PIP is fully rolled out, this means many will also lose their ability to transport themselves and other family members to hospital or primary care services⁸.

4. Recommendations

- 4.1 Disabled people should have the same rights, choice and opportunity in accessing health services – and achieving positive health outcomes – as non-disabled people. To do this, healthcare must be based on the principles of equality and human rights and that all human life is of value (see section 1 above). It must be delivered in a way that recognises the role of healthcare in ensuring disabled people can participate in society and lead an ordinary life.
- 4.2 We note that despite evidence of discrimination and poorer outcomes for disabled people, policy and practise on health inequalities continues to focus on health differences linked to geographical area. We urge the Scottish Government to ensure that all interventions seeking to improve health outcomes take specific account of the circumstances of disabled people – and other communities of interest.
- 4.3 To do this, we suggest robust data gathering about disabled people and people accessing interventions. We note that gathering such data will also help organisations to comply with the Equality Act 2010. We suggest also that this be used to drive a targeted approach e.g. targets for reductions in early deaths of learning disabled people and so on.
- 4.4 Eligibility for social care services should be reviewed urgently to take account of the impact of isolation and prevention on health outcomes.
- 4.5 All frontline staff and management in the National Health Service should receive Disability Equality Training delivered by disabled trainers with personal experience of using NHS services.
- 4.6 Working in coproduction with disabled people and their directly accountable organisations (DPOs) will be essential for this – without this, a full understanding of the circumstances of disabled people, and thus the impact of any interventions, will be impossible. We suggest the ILiS guide to coproduction is a useful tool for making this happen⁹.

Independent Living in Scotland
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⁸ “Driving Change”, Age Scotland

⁹ www.ilis.co.uk