



Information Brief 4

Accessing Services and Supports for People and Families with Disabilities

- 1. Key Statistics**
- 2. The Lived Reality – The Issue in Short**
- 3. Accessing Services and Supports in More Detail**

1. Key Statistics

- 68% of people who use disability services in Ireland are dissatisfied with the level of control they have over their own lives. 40% are very dissatisfied with the quality of those services.ⁱ
- 29% of people in Ireland disagree that people using disability services are treated with respect for their dignity.ⁱⁱ
- In April 2015, 21,821 people remained on waiting lists for speech and language assessments and interventions.ⁱⁱⁱ
- More than 15,300 people were waiting for assessment by an Occupational Therapist (OT), with 2,409 children waiting for over a year.^{iv}
- 38% of carers who look after someone in the same household report feeling completely overwhelmed by their caring responsibilities.^v

2. The Lived Reality – the Issue in Short

1. Denying people access to or forcing them to wait long periods for regular or individualised therapies leads to people falling short of their capacity or, in some cases, disimprove in their health, well-being and skills.
2. Between 2008 and 2014, cuts of €159 million to disability services in Ireland were enforced, representing a 9% reduction in spending – and that’s before inflation.^{vi}
3. Waiting for essential services is a way of life for people with disabilities. In April 2015, 21,821 people remained on waiting lists for speech and language assessments and interventions.^{vii}
4. In desperation, many people are forced to purchase health therapy services privately and bear this expense on top of the extra cost of disability.
5. 10% of people with disabilities have experienced discrimination when accessing health services between 2012 and 2014 alone,^{viii} and 29% of people in Ireland disagree that people using disability services are treated with respect for their dignity.^{ix}
6. The number of carers in Ireland has massively increased. However, between 2008 and 2014, the weekly Carers Allowance was reduced by almost 8% - or €16.30. In that same time, the Respite Care Grant was cut by 19% - from €1,780 to €1,375.

3. Accessing Services and Supports in More Detail

Insufficient access to health services and supports

Open, reliable access to health services and supports is essential to enable people with disabilities to live with well-being. A strong health service brings a positive impact to every area of your life: the better your condition and treatment, the better able you are to live your life most fully.

Regular and individualised therapies - and particularly early intervention - helps to improve people's ability to communicate their needs, to develop their Independent Living skills, to engage their social skills and foster friendships, to increase their inclusion and participation in the community, as well as to improve their educational and employment outcomes. Denying people access to or forcing them to wait long periods for such therapies leads to people falling short of their capacity or, in some cases, disimprove in their health, well-being and skills; it prevents people from making the most of their medical condition or impairment so that they can get on with life, just like everyone else.

Sadly, that is an experience that too many people with disabilities are met with here in Ireland. 40% of people using disability services in the country are very dissatisfied with the quality of those services – and 68% are dissatisfied with the level of control they have over their own lives.^x This isn't just an issue of comfort or satisfaction – this is an issue of rights!

We can no longer sit back and watch a situation where resources are put before people, or where waiting lists are growing, inconsistencies spreading, communications closing and costs to the individual rising. Between 2008 and 2014, cuts of €159 million to disability services in Ireland were enforced, representing a 9.4% reduction in spending – and that's before we include inflation.^{xi} No Budget yet

has managed to adequately restore these significant cutbacks, and the effect is most keenly felt by people with disabilities in their everyday lives.

Prolonged waiting lists for therapies

Waiting to access essential therapies – or even to be assessed for them – is all too familiar for people with disabilities and their families. Concerningly, without investment or reform, the situation looks set to worsen quite significantly. There were over 12,000 fewer Health Service Executive (HSE) staff in December 2013 than at the height of public health sector employment in 2007^{xii}, with another 2,600 expected to be gone by the end of last year.^{xiii} Adding such falls in staff numbers to the reduced spending and increased waiting lists over the last number of years will only deteriorate an already stressed system

SLT and OT are basic and essential therapies that are crucial to the development of skills for everyday life. SLT enables people with communication disorders and swallowing disorders to achieve their maximum potential, while OT enables people to participate in the activities of everyday life: for example, dressing, eating, bathing, and more.

In desperation over these long waiting lists and the inadequacy of the services, many people are forced to purchase health therapy services privately and bear this expense on top of the extra cost of disability. This has to change.

Lasting discrimination and indignity

The right to be free from discrimination is a fundamental one, protected both nationally and internationally by countless conventions and policies. However, 10% of people with disabilities have experienced discrimination when accessing health

services between 2012 and 2014 alone^{xiv}, and 29% of people in Ireland disagree that people using disability services are treated with respect for their dignity.^{xv}

Scarce family and carer supports

Families and carers play a crucial and ever-growing role in the care and support of people with disabilities and disabling conditions right across the country. The number of carers in Ireland, for example, jumped by over 16% - from 160,917 to 187,112 - in the five years between 2006 and 2011 alone.^{xvi}

At the same time, however, recognition and support for this group of people has diminished. Between 2008 and 2014, the weekly Carers Allowance was reduced by almost 8% - or €16.30. In that same time, the Respite Care Grant was cut by 19% - from €1,780 to €1,375.^{xvii}

This does far too little to alleviate or offset the volume of work and support that families and carers give. Family carers come at every life stage. Over 4,000 – or 4,228 – children aged under 15 years provide care to others, with the number of unpaid care hours given by children totalling at 38,496 every week.^{xviii} Meanwhile, people aged 70 and over provide 795,916 hours of unpaid care per week, and a fifth of those are offering full-time care.^{xix}

15,175 people give '24/7' care, coming to over two and a half million – or 2,549,400 – care hours every single week, and 38% of carers who look after someone in the same household report feeling completely overwhelmed by their caring responsibilities.^{xx}

Many families are compelled to provide such levels of care for a person with a disability because the services and supports available to them are so lacking. About 11% of childcare service providers, for example, have had to refuse a place to children with disabilities because they lacked the additional staff, space or specialist supports to meet the children's needs.^{xxi}

More has to be done to ensure that families and carers are fully supported in their roles and that the value of everything that they do is wholly and fairly recognised.

ⁱ Department of Health (2010) Report on Public Consultation: Efficiency and Effectiveness of Disability Service in Ireland. Dublin: Department of Health

ⁱⁱ Irish Human Rights and Equality Commission (2015) Awareness of and Attitudes to Human Rights and Equality. Red C

ⁱⁱⁱ Figures were provided to Roisin Shorthall, TD, through a Parliamentary Question (PQ Ref. No. 18511/15)

^{iv} Figures were provided to Roisin Shorthall, TD, through a Parliamentary Question (PQ Ref. No. 18511/15)

^v Census 2011 Profile 8 Our Bill of Health

^{vi} Disability Federation of Ireland (DFI) Pre-Budget Submission 2016: No Recovery Without Us

^{vii} Figures were provided to Roisin Shorthall, TD, through a Parliamentary Question (PQ Ref. No. 18511/15)

^{viii} CSO, QNHS, August 2015 <http://www.cso.ie/en/releasesandpublications/er/q-eq/qnhsequalitymodulequarter32014/>

^{ix} Irish Human Rights and Equality Commission (2015) Awareness of and Attitudes to Human Rights and Equality. Red C

^x Department of Health (2010) Report on Public Consultation: Efficiency and Effectiveness of Disability Service in Ireland. Dublin: Department of Health

^{xixi} Social Justice Ireland (2014) Budget Analysis and Critique, Available at

<http://www.socialjustice.ie/content/publications/budget-2015-analysis-and-critique>

^{xii} HSE 2014. HSE National Service Plan 2014 Dublin HSE.

^{xiii} HSE 2013. HSE July 2013 Performance Report Dublin: HSE.

^{xiv} CSO, QNHS, August 2015 <http://www.cso.ie/en/releasesandpublications/er/q-eq/qnhsequalitymodulequarter32014/>

^{xv} Irish Human Rights and Equality Commission (2015) Awareness of and Attitudes to Human Rights and Equality. Red C

^{xvi} Census 2011 Profile 8 Our Bill of Health - Health, Disability and Carers in Ireland

^{xvii} Social Justice Ireland (2014) Budget Analysis and Critique, Available at

<http://www.socialjustice.ie/content/publications/budget-2015-analysis-and-critique>

^{xviii} Census 2011 Profile 8 Our Bill of Health - Health, Disability and Carers in Ireland

^{xix} Census 2011 Profile 8 Our Bill of Health - Health, Disability and Carers in Ireland

^{xx} Census 2011 Profile 8 Our Bill of Health

^{xxi} Early Childhood Ireland (2013) <https://www.earlychildhoodireland.ie/policy-research-and-media/research/surveys/results-of-the-special-needs-survey/>