

Disability Federation of Ireland (DFI)

Presentation to the Joint Committee on Health

**Review of Services for those Living with a
Neurological Condition**

8th May 2019

Introduction

DFI is the national support organisation for (120+) voluntary disability organisations in Ireland who provide services to people with disabilities and disabling conditions. We work to create an Ireland where everyone can thrive, where everyone is equally valued.

We also work with a growing number of other organisations that have a significant interest in people with disabilities.

DFI provides:

- Information
- Training and Support
- Networking
- Advocacy and Representation
- Research, Policy Development and Implementation
- Organisation and Management Development

DFI welcomes the opportunity to come before this Committee to review services for those living with a neurological condition.

Who are the 'disability' in Ireland?

According to Census 2016 13.5% of the population, or 643, 131 people in Ireland identify as having at least one disability. We know:

- 1 in 4 people of working age will acquire a disability- and there is a strong neurological bias to this onset
- This means most of these are likely already in work, married or in a relationship and have families of their own.

Most people with disabilities acquire their disability in adulthood; many of these are neurological in nature. Timely access to neuro-rehabilitation services post onset of the condition will directly impact on whether a person can sustain their jobs, family commitments and relationships. Research has shown how early access to clinical neurorehabilitation services has a significant impact on the health outcomes for those who acquire neurological condition and we fully endorse the NAIs call for greater investment to neurological and neurorehabilitation services.. However, DFI is also of the view to sustain these health benefits people require a range of community services and supports that is well funded and can be trusted on to shadow the individual and their family as they navigate the new world post diagnosis.

What a Community Services Programme would look like?

We currently spend €1.9 billion in disability health and personal social services in Ireland. In 2019, 85% of the HSE disability budget supports over 8,500 people through a range of residential supports and 27,000 people in day places (HSE Service Plan 2019). Clearly the numbers in receipt of these core disability services fall significantly short of the 643,000 people with disabilities identified in the Census 2016. The reality is that the majority of people with disabilities in Ireland continue to live at home, accessing a mix of services and supports via primary and community disability services, quite separate from the core Disability Services Programme.

Figures contained in a report prepared for the Department of Health Value for Money Review in 2017 also reinforce this analysis:

Disability Services Budget 2017	€m	% of budget	No. of users
Residential	1,064.1	63%	8,371
Day Services	364.4	22%	18,000
Respite	41.6	2%	6,320
Personal Assistance and Home Supports	79	5%	9,784
Multi-disciplinary Services	86.4	5%	
Other Community Services and Supports	52.7	3%	
Net Total	1,688.2	100%	

Value for Money and Policy Review of Disability Services – Working Group 1 Report 2017

This breakdown of disability spend against programme type shows community services and supports, which include those provided to people living with neurological conditions, account for less than 10% of the overall HSE disability budget.

Community services and supports are mostly cofounded by a range of disability organisations, many of who are condition specific. They help individuals and families to navigate the diagnose and develop strategies for managing their condition, access a range of services from acute and primary health care services, housing supports services, social welfare services and local educational and training opportunities for instance.

Although complementary to clinical neurorehabilitation services these services are distinctive in nature and include: Personal Assistants

- Home Supports
- Family support workers
- Health and wellbeing included the provision of accredited self management courses mm
- Information health lines
- Summer camps, respite services, youth groups etc

By supporting individuals and families to manage the condition these organisations are an integral part of the health supports infrastructure. To plan for clinical neurorehabilitation services without equally putting in place the community supports to sustain a persons wellbeing and reducing the risk of relapse is short-sighted. The value of these services will now be outlined by my colleague Ava Battles, CEO of the MS Society in Ireland.

Call for a targeted investment in a coherent Community Disability Services

Programme:

DFI has two specific asks of this Committee:

1. To secure commitment in Budget 2020 to a five year Multi – Annual Investment Programme of €200m per year for a range of services. This ask is in in line with the Department of Health’s report of the Transforming Lives Working Group 1 – “Forecasting Future Demand for Disability Services”
2. To commit to the development of a strategy for community services and supports that will complement existing services offered through clinical neuroadaptation services, primary care and disability services.

Slaintecare identifies the need for greater synergy across the health system. The Value for Money Policy Review commits to supporting people to live ordinary lives in ordinary places. Organisations such as MS and others deliver critical continuing services and supports to people with disabilities and chronic conditions in their own homes and local communities.

The 600,000 people with disabilities dependent on these services deserve the security of knowing that you too understand the value their services and will look to establish a sustainable funding stream to support their development and delivery. that there is a plan can relay on these services and supports as they continue to manage their condition.

DFI is about making Ireland fairer for people with disabilities.

We work to create an Ireland where everyone can thrive, where everyone is equally valued.

We do this by supporting people with disabilities and strengthening the disability movement.

There are over 120 member organisations in DFI. We also work with a growing number of other organisations that have a significant interest in people with disabilities.

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Disability is a societal issue and DFI works with Government, and across all the social and economic strands and interests of society.

Disability Federation of Ireland, Fumbally Court, Fumbally Lane, Dublin 8 Tel: 01-4547978, Fax: 01-4547981 Email: info@disability-federation.ie Web: www.disability-federation.ie Follow us on Facebook and Twitter.

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