



Neurological Alliance of Ireland

Response to the Call for Submissions on the Lived Experience of People with Disabilities

Joint Oireachtas Committee on Disability Matters

November 2020

Executive Summary

The Neurological Alliance of Ireland is the national umbrella organisation representing over thirty charities working with people with neurological conditions. This submission focuses on the lived experience of Irish people with neurorehabilitation needs arising from an acquired neurological disability.

This submission notes that:

- Over 800,000 Irish people are estimated to live with a neurological condition¹ such as acquired brain injury, stroke, multiple sclerosis, Parkinson's disease and epilepsy. Neurological conditions are now the leading cause of disability worldwide according to the World Health Organisation².

-The UNCRPD calls on states to provide comprehensive habilitation and rehabilitation services to people with disabilities: beginning at the earliest possible stage and supporting inclusion and participation in communities³

-Neurorehabilitation services in Ireland are completely underdeveloped and underresourced leading to unnecessary disability and lost opportunities for recovery, social participation and employment. COVID19 has exacerbated the crisis in neurorehabilitation by reducing access to services and threatening the future of community neurodisability services provided by the voluntary sector

-A three-year implementation framework⁴ (2019-2021) for the National Neurorehabilitation Strategy is due to end next year 2021. Implementation of this framework is a key action within the Slaintecare Action Plan⁵ and commitment within the current Programme For Government⁶. Despite this, implementation to date has made little or no progress in seven of nine community health organisations (CHOs)

Ireland is not meeting its responsibilities under the UNCRPD to provide habilitation and rehabilitation services to people with acquired neurodisabilities and will continue to fail to do so unless there is immediate priority action to implement existing policy and invest in new and existing services.

The Neurological Alliance of Ireland is calling for:

1. The Neurological Alliance of Ireland is calling for the implementation of the Framework for the National Neurorehabilitation Strategy to be prioritised within the HSE service plan for 2021 as COVID19 introduces a further demand for neurorehabilitation services.
2. The vast proportion of community-based rehabilitation and long-term care for people with neurodisability in Ireland is provided by the voluntary sector. COVID19 has decimated the public fundraising these organisations rely on to part-fund service provision. The

¹ Strategic Review of Neurology and Neurophysiology Services in Ireland (2007) National Hospitals Office

² Consolidated Report by the Director General (May 2020) World Health Organisation: Pages 8-9
https://apps.who.int/gb/ebwha/pdf_files/WHA73/A73_5-en.pdf

³ Article 26 Un Convention on the Rights of People with Disabilities (Habilitation and Rehabilitation Services)
<https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>

⁴ National Policy and Strategy for the Provision of Neurorehabilitation Services in Ireland: From Theory to Action: Implementation Framework 2019-2021 (February 2019) Health Services Executive

⁵ Slaintecare Action Plan (2019) Department of Health

⁶ Programme for Government: Our Shared Future (June 2020) www.gov.ie

Neurological Alliance is calling for a moratorium on cuts to disability funding and additional funding to address the long-standing deficits among voluntary providers.

About the Neurological Alliance of Ireland

The Neurological Alliance of Ireland is the national umbrella body for over thirty not for profit organisations working with people with neurological conditions. It aims to promote the development of services and supports for people with neurological conditions in Ireland through advocacy, policy development, awareness and research.

UN Convention on the Rights of People with Disabilities and Neurorehabilitation Needs

This submission focuses on Article 26 of the UN Convention on the Rights of People with Disabilities: Habilitation and Rehabilitation Services from the perspective of Irish people living with an acquired neurodisability.

Article 26: States Parties shall take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain independence, full physical, mental, social and vocational ability and full inclusion and participation in all aspects of life. To that end, State Parties shall organise, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services, in such a way that these services and programmes:

- (a) Begin at the earliest possible stage and are based on the multidisciplinary assessment of individual needs and strengths*
- (b) Support participation and inclusion in the community and all aspects of society, are voluntary and are available to persons with disabilities as close as possible to their own communities, including in rural areas.*

2. States Parties shall promote the development of initial and continuing training for professionals and staff working on habilitation and rehabilitation services

States Parties shall promote the availability, knowledge of and use of assistive devices and technologies, designed for persons with disabilities as they relate to habilitation and rehabilitation.

The Lived Experience of Irish People with Neurorehabilitation Needs

Neurorehabilitation is critical for the long-term recovery of people who have, for example, had a stroke or acquired brain injury, as well as minimising the long-term impact of progressive neurological conditions.

The need for a continuous pathway of services and supports for the neuro-rehabilitation journey cannot be stressed enough. There is a vital “window” in which to provide neuro-rehabilitation following conditions such as stroke and acquired brain injury and to prevent further deterioration in the case of progressive neurological conditions. Any gaps and delays in the neuro-rehabilitation process can result in a devastating impact for these individuals and their families.

Delays and gaps in the neurorehabilitation journey are not just unacceptable, they have life changing consequences for people with neurological conditions and their families.

Over 800,000 Irish people are estimated to be living with neurological conditions with an additional 40,000 newly diagnosed each year. Most people diagnosed with a sudden onset (stroke, acquired brain injury) or progressive (multiple sclerosis, Parkinson's disease) neurological condition will require some degree of specialist neurorehabilitation intervention. It is estimated that only one in six Irish people with neurological conditions will receive the specialist rehabilitation they need.

The current patient journey for people with neurorehabilitation needs is characterised by:

- Long Delays in Accessing a Post-Acute Neurorehabilitation Bed with some patients missing out on this altogether or spending much of their vital window for recovery in an acute hospital bed with very limited or no structured rehabilitation taking place

- Increasing pressure on post-acute beds providing patients with time-limited access to inpatient specialist neurorehabilitation

- Lack of community neurorehabilitation teams means that people are dependent on general community and primary care services for therapy provision (speech and language therapy, occupational therapy etc) The high demand on these services mean that people with neurorehabilitation needs have only a fraction of their requirements met in the community: if they receive a service at all.

- The dearth of long-term day, vocational and residential services in the community mean that many people with neurorehabilitative needs are inappropriately placed in nursing homes or living at home with little of any supports.

The Implementation Framework for the National Neurorehabilitation Strategy provides an example of one individual's journey which highlights the huge gaps and critical underresourcing of specialist neurorehabilitation services. This individual:

- waited 55 days for a rehabilitation assessment after experiencing a sudden onset neurological event

- waited 332 days for a bed to become available in the National Rehabilitation Hospital

- subsequently was discharged back to an acute hospital because of the lack of appropriate step-down facilities and pressures on the NRH bed and remained there for a subsequent 122 days.

Neurorehabilitation Services in Ireland

Neurorehabilitation services are a continuum based on the needs of the individual at different stages of their neurological condition. People with sudden onset neurological conditions (stroke, acquired brain injury) typically require a period of intensive specialist rehabilitation in an inpatient unit followed by a range of long-term neurorehabilitation supports and services in the community. People with progressive neurological conditions such as multiple sclerosis or Parkinson's disease may experience

sudden or gradual changes in their condition requiring ongoing neurorehabilitative support to maintain their existing level of function for as long as possible and avoid hospitalisation.

The landscape for neurorehabilitation services in Ireland has remained largely unchanged since the launch of the Neurorehabilitation Strategy in 2011. There is one national tertiary centre at the National Rehabilitation Hospital. In the absence of other specialist rehabilitation services, both inpatient and community based, most of those with neurorehabilitative needs are referred to this service.

The new hospital development at the NRH site will not contribute additional beds to the system and while small specialist rehabilitation units are in development in areas such as Roscommon and hospitals such as Peamount, these cannot address the huge deficit in specialist rehabilitation beds at less than half that required for the Irish population.

With demand far outweighing capacity, waiting times for access to the NRH can range from three months to two years and the majority of those waiting are accumulating bed days in the acute hospital- services. The framework points to the need for additional specialist inpatient units around the country that would provide both a 'step down' service for patients of the national tertiary centre, but also a 'step up' facility for those living in the community with neurological conditions requiring intermittent admissions for intensive rehabilitation services.

Investment in community neuro-rehabilitation services and long term supports for people with neurological conditions are also critical in order to provide effective integrated care at every stage of the neuro-rehabilitation pathway. Post-acute rehabilitation such as that provided in the National Rehabilitation Hospital is just one part of a continuum of care for people with neuro-rehabilitation needs and it cannot provide its services in a vacuum without the services in the community to maintain the goals of the rehabilitation process. All too often, the committed work of the rehabilitation team, and the individual and their family, is lost because of a lack of proper services in the community once the person is discharged.

Six out of nine Community Health Organisation (CHO) areas have no community neurorehabilitation team in place, the remainder have only partially staffed teams. Community neurorehabilitation teams provide a period of intensive rehabilitation, typically over six to twelve weeks in duration. However, people with neurorehabilitation needs are often adjusting to living the rest of their lives with neurodisability. Long term neurorehabilitation services in the community include residential care including long-stay and transitional rehabilitation units, home rehabilitation (including intensive home care packages, day rehabilitation services, vocational rehabilitation, family support and case manager/key worker services).

There is a huge dearth of these services in the community, resulting in people with neurorehabilitation needs "falling off a cliff" in the words of one family because of a lack of follow on care once they are discharged from hospital. There is evidence that access to neurorehabilitation services in the community is actually becoming more difficult. The "Living with a Neurological Condition in Ireland"⁷ survey series carried out by the Neurological Alliance of Ireland from 2011 to 2020 examines access to a range of basic supports for people with neurological conditions. As an example, the percentage of people reporting that they cannot access physiotherapy services (a key component of community-based neurorehabilitation services) has doubled from 9% in 2011 to 18% in 2019.

⁷ Living with a Neurological Condition in Ireland (2020) Neurological Alliance of Ireland Summary Findings <https://www.nai.ie/go/news/12-3-2020-launch-of-latest-nai-research>

Vocational Rehabilitation and Employment for People with Acquired Neurodisability

Ireland has one of the lowest employment rates in the EU for people with disabilities⁸

The dearth of vocational neurorehabilitation services mean that this is a particular problem for people with acquired neurodisability who are often of working age and experience huge challenges to sustain employment or re-enter the workplace.

Social Participation and Engagement in Communities

Acquired neurodisability is often invisible and people experience significant barriers to integration, leading to isolation and loneliness among individuals and their families⁹

People with long term neurological conditions have the lowest health-related quality of life of any long- term health condition¹⁰. The lack of access to neurorehabilitation services, particularly in the community, continues to deny people with neurological conditions the opportunities that are available to the rest of Irish society: to engage in social activities and to participate as active members within their own communities. Neurological disability is often referred to as the “invisible disability¹¹”.

Accommodating People with Neurodisability in Nursing Homes

People with neurorehabilitation needs will only spend a short time in acute or post-acute hospitals or rehabilitation units. There is a critical dearth of options for people with acquired neurodisability in Ireland when it comes to their residential needs: both short and long term.

Appropriate step-down care, transitional living units, assisted living facilities and home care supports are unavailable to Irish people with disabilities (including acquired neurodisabilities) who require them. As a result, people are accommodated in nursing homes which are entirely unsuitable for their needs. For those with neurorehabilitation needs, the problem is exacerbated as community-based neurorehabilitation teams, where they exist, do not provide a service to nursing home residents. This means that these individuals are further disenfranchised when it comes to their access to neurorehabilitation services. A study commissioned by the Disability Federation of Ireland in 2018¹²

⁸ https://ec.europa.eu/info/sites/info/files/file_import/2019-european-semester-country-report-ireland_en.pdf

⁹ Living with an acquired brain injury: Barriers to developing community supports as a basis for independent living (2014) National Disability Authority

¹⁰ <https://www.england.nhs.uk/ourwork/clinical-policy/lrc/our-work-on-long-term-conditions/neurological/>

¹¹ The invisible patients: revealing the state of neurology services (July 2015) Neurological Alliance UK

¹² The situation of younger people with disabilities living in nursing homes in Ireland: Phase 1 Report (2018) Report Commissioned by the Disability Federation of Ireland https://www.disability-federation.ie/assets/files/pdf/dfi_rr_2018_web.pdf

of people with disabilities under 65 years accommodated in nursing homes, found that this is predominantly due to the lack of other more appropriate options for their care.

The Policy Response to the Irish People Living with Neurorehabilitation Needs

A National Strategy for the Provision of Neurorehabilitation Services in Ireland was published in 2011. After almost a decade of delays, a three- year implementation framework for the strategy was finally published in February 2019. Implementation of this framework is a key action within the Slaintecare Action Plan and commitment within the current Programme For Government. The framework, which is due for completion next year, has so far seen only limited investment in two Community Health Organisations with no new services in any of the other CHOs nationwide. A third of CHOs have made no progress in commencing implementation of the framework.

Neurorehabilitation Services for Children with Neurodisability

While this submission deals primarily with the neurorehabilitation needs of adults (over 18 years) with acquired neurodisability: there is a huge dearth of services for children with neurorehabilitation requirements. We appreciate the expertise of Dr Irwin Gill, Paediatric Consultant in Neurodisability in providing this review of paediatric neurorehabilitation services below:

Dedicated rehabilitation services for children in Ireland are close to non-existent. A total of 1.25 WTE consultant paediatrician posts are allocated for rehabilitation; all of these are located in Dublin. By comparison, there are 11 adult rehabilitation specialists in Ireland- while this is substantially more, it is only 10% of the European average. This illustrates the degree of understaffing in paediatric rehabilitation.

There are 8 dedicated inpatient rehabilitation beds for children, all located in the National Rehabilitation Hospital, compared to approximately 100 tertiary beds for adults in the same facility. The NRH has recently been modernised but capacity for children has only increased by 2 beds.

Outside of the National Rehabilitation Hospital, rehabilitation services in acute paediatric hospitals are provided from within pre-existing resources rather than by HSCP (health and social care) posts dedicated for rehabilitation.

The impact on children and families is a lack of expertise, disjointed and inconsistent care, long waiting times for all services, and less positive outcomes than would happen in an evolved system.

2,500 children in Ireland suffer traumatic brain injuries every year- many more are affected by stroke, meningitis, brain tumours and other causes of non-traumatic brain injury.

It is common for children in tertiary hospitals like Children's Health Ireland at Temple Street to wait over 6 months for admission to the NRH following a severe brain or spinal cord injury. This is purely because of limited capacity. Furthermore, because of a lack of paediatric rehabilitation teams in regional hospitals (and the chronic underinvestment in community disability services) it is usually not possible to transfer patients from tertiary hospitals to regional hospitals closer to families' home address. This significantly increases the burden and stress on these families during their admissions; these long admissions also increase bed occupancy, preventing elective admissions to the tertiary centres for surgeries and lengthening waiting times.

The steps required to remedy this situation are:

1. Immediately progress to Phase 2 of the expansion plan for the NRH with emphasis on expanding capacity for children.
2. Investing in dedicated rehabilitation teams at the NRH and in tertiary paediatric hospitals.
3. Developing regional rehabilitation teams to allow for young people to receive care closer to home, consistent with Slaintecare principles.
4. Increasing funding for brain injury advocacy groups (ABI Ireland, Headway) who currently are forced to exclude children from their services due to limited resources.
5. Standardising the process of liaising with schools at discharge from hospital for all children admitted with head injuries, whose subsequent difficulties often go unrecognised or are misunderstood in the classroom.
6. Developing a National Paediatric Rehabilitation Plan analogous to that recently published for adult services.
7. Enmeshing rehabilitation in a National Paediatric Trauma Plan, analogous to that recently published for adult services.
8. To include children in a national dataset of rehabilitation outcomes based upon standardised outcomes measures, as is standard practice in other countries (e.g. UKROC).

2020: A Worsening Crisis in Neurorehabilitation Services

This submission has outlined that neurorehabilitation services are completely under resourced and underdeveloped resulting in unnecessary disability and lost opportunities for thousands of Irish people with acquired neurodisability.

COVID19 has further worsened an already critical situation due to the following factors

1) Funding Crisis Among Voluntary Providers of Neurodisability Services

In Ireland two thirds of disability services are provided by not for profit organisations¹³. However, in the case of neurodisability services, this percentage is likely to be much higher with the vast proportion of community-based rehabilitation and long-term care provided by the not for profit sector. This submission has outlined that neurorehabilitation services are already completely inadequate to meet current need. Any curtailment of service provision by the voluntary sector due to lack of sufficient funding to maintain services will have a disproportionate impact on people with neurodisabilities. COVID19 has decimated the public fundraising these organisations rely on to part-fund service provision¹⁴. Many voluntary providers of neurodisability services were already running a deficit due to successive annual cuts to disability funding and failure to fund Section 39 organisations to the real cost of providing services.

2) Lack of Access to Neurorehabilitation During Lockdown

Neurorehabilitation services, already completely inadequate pre-COVID-19 are now faced with increased demand to meet the backlog of new and existing patients who were unable to access neurorehabilitation services during lockdown. This was due to a combination of factors (i) patients discharged early from acute hospitals and who didn't get access to post-acute rehabilitation in the acute setting due to the COVID-19 outbreak, (ii) patients who did not get access to rehabilitation because of early discharge home (rehabilitation facilities were only admitting from acute hospitals) and (iii) patients with neurorehabilitation needs who had limited or no services in the community due to the redeployment of health and social care professionals.

A survey of over 600 Irish people with neurological conditions found that COVID19 had significantly reduced access to neurorehabilitation services, particularly community-based services¹⁵.

3) New Demand for Neurorehabilitation Services among those recovering from COVID19

Evidence is increasingly emerging that COVID-19 is a disease with significant neurological consequences with over a third of patients experiencing neurological sequelae^{16 17}. Neurological consequences with a long-term impact include cerebrovascular events (stroke), hypoxia, extreme

¹³ Disability Action Coalition (2020) <https://tdac.ie/publications/>

¹⁴ COVID19 Impact Survey (2020) Charities Institute Ireland

¹⁵ COVID19: The impact on people with neurological conditions and family carers (May 2020) Neurological Alliance of Ireland https://www.nai.ie/assets/42/09A425FC-94A6-4F82-8CD3A32F19F95592_document/COVID-19_Survey_Report_2020.pdf

¹⁶ Henecka et al (2020) Immediate and Long term consequences of COVID-19 infections for the development of neurological disease. *Alzheimer Research & Therapy* (12) 69 (April 2020)

¹⁷ Lancet Editorial: The Neurological Implications of COVID-19. June 2020 (19)

fatigue and cognitive impairment. These effects and the direct impact on those recovering from COVID-19 were outlined in a recent feature in the Irish Times¹⁸

Long-term neurological complications arising from COVID-19 which will require access to specialist neurorehabilitation services¹⁹, a service that is completely underdeveloped to meet existing demand and certainly in no position to mobilise an adequate response to COVID-19 based on current levels of resourcing. People with chronic neurological disease have been shown to be at greater risk of worse outcomes from COVID19²⁰, placing additional pressure on already under resourced neurological care services across the board.

The Neurological Alliance of Ireland is concerned that:

-Existing neurorehabilitation services are inadequate to meet current demand and cannot meet the needs of this new group of patients

-People with neurorehabilitation needs have long been disenfranchised with limited access to the services they require. They face further limitations as services come under increasing pressure with post COVID patients requiring neurorehabilitation services.

¹⁸ <https://www.irishtimes.com/life-and-style/health-family/covid-and-the-brain-this-has-taken-almost-everything-that-is-me-away-from-me-1.4343793>

¹⁹ Rehabilitation in the Wake of COVID-19: A phoenix from the ashes. British Society of Rehabilitation Medicine (BSRM) April 2020

²⁰ Differences in risk of severe outcomes from COVID19 across occupations in Ireland (July 2020) Economic and Social Research Institute (ESRI) Ireland

Recommendations

Ireland is currently failing to meet its responsibilities under the UNCRPD to provide habilitation and rehabilitation services to people with acquired neurodisabilities and will continue to fail to do so unless there is immediate priority action to implement existing policy and invest in new and existing services.

The Neurological Alliance of Ireland is calling for:

1. IMPLEMENTATION OF THE NEUROREHABILITATION FRAMEWORK AS A PRIORITY WITHIN THE 2021 HSE SERVICE PLAN

The Neurological Alliance of Ireland is calling for the implementation of the Framework for the National Neurorehabilitation Strategy to be prioritised within the HSE service plan for 2021.

This is in recognition of:

-2021 represents the final year of the three-year framework which has seen little or no progress in the majority of areas of the country

-the continued lack of investment in neurorehabilitation services is contributing to increased disability and lack of opportunities for recovery and engagement in society among those with neurorehabilitation needs

-COVID19 has placed additional pressure on existing neurorehabilitation services as well as creating a new need additional need for specialist rehabilitation that cannot be met within existing services.

2. ACTION TO ADDRESS THE FUNDING CRISIS AMONG VOLUNTARY PROVIDERS OF SERVICES TO PEOPLE WITH NEURODISABILITY

In Ireland two thirds of disability services are provided by not for profit organisations²¹. However, in the case of neurodisability services, this percentage is likely to be much higher with the vast proportion of community-based rehabilitation and long-term care provided by the not for profit sector. This submission has outlined that neurorehabilitation services are already completely inadequate to meet current need. Any curtailment of service provision by the voluntary sector due to lack of sufficient funding to maintain services will have a disproportionate impact on people with neurodisabilities.

COVID19 has decimated the public fundraising these organisations rely on to part-fund service provision. Many voluntary providers of neurodisability services were already running a deficit due to successive annual cuts to disability funding and failure to fund Section 39 organisations to the real cost of providing services. While the Neurological Alliance welcomes the announcement in the recent Budget of an additional €20m in funding to voluntary disability providers, this will not even address pre-COVID19 deficit levels.

The Neurological Alliance is calling for a moratorium on cuts to disability funding and additional funding to address the long-standing deficits and the impact of COVID19 among voluntary providers.

²¹ Disability Action Coalition (2020) <https://tdac.ie/publications/>

NAI member organisations

Acquired Brain injury Ireland
Alzheimer Society of Ireland
An Saol
Aphasia Ireland
Ataxia Ireland
Aware
Bloomfield Health Services
Cheshire Ireland
Chronic Pain Ireland
Dystonia Ireland
Enable Ireland
Epilepsy Ireland
Headway
Huntington's Disease Association of Ireland
Irish Heart Foundation
Irish Hospice Foundation
Irish Motor Neurone Disease Association
Migraine Association of Ireland
Move4Parkinsons
Multiple Sclerosis Society of Ireland
Muscular Dystrophy Ireland
National Council for the Blind
Neurofibromatosis Association of Ireland
North West MS Therapy Centre
Parkinson's Association of Ireland
Polio Survivors Ireland
PSPA Ireland
Spinal Injuries Ireland
Spina Bifida Hydrocephalus Ireland
The Rehab Group

Associate Members

Brain Tumour Ireland
Syringomyelia Chiara Malformation Support Group