

**RESPONSE TO THE CALL
FOR SUBMISSIONS TO
THE DRAFT INITIAL STATE
REPORT UNDER THE UN
CONVENTION ON THE
RIGHTS OF PEOPLE WITH
DISABILITIES**

**DEPARTMENT OF CHILDREN, EQUALITY,
DISABILITY, INTEGRATION AND YOUTH**

MARCH 2021

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 response in the initial State Report to Article 26¹ of the UNCRPD.

The draft State report outlines progress in meeting commitments under Article 26 through the following:

1. Publication of a three-year Implementation Framework for the 2011 National Neurorehabilitation Strategy

2. Establishment of a National Steering Group for implementation of the National Neurorehabilitation Strategy

3. Redevelopment of the National Neurorehabilitation Strategy.

This submission contends that the content of the Draft Report as it stands fails to provide a realistic assessment of the lack of progress to date on implementation of existing policy and also fails to convey the reality of the huge gaps that still exist in neurorehabilitation services

across all stages of the patient journey. Implementation of a three-year framework for the National Neurorehabilitation Strategy² has been extremely limited and has failed to date to provide any additional services outside the east of the country while the redevelopment of the National Rehabilitation Hospital has provided none of the additional one hundred and fifty specialist rehabilitation beds critically required to meet the needs of our population. Implementation of the Neurorehabilitation Strategy represents a key commitment of both the current Programme for Government³ and the

Slaintecare Action Plan⁴. Despite this, there has been little or no progress in addressing the serious gaps in neurorehabilitation services since the strategy was published a decade ago. The Neurological Alliance of Ireland is calling for the current reporting on Article 26 in the Draft Report to be revised to reflect the significant work that must be done to implement existing policy and to provide for successive Implementation Frameworks beyond 2021 in order to fully implement the National Neurorehabilitation Strategy.

¹ 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.

² National Policy & Strategy for the Provision of Neurorehabilitation Services in Ireland (2011) Department of Health

³ Programme for Government: Our Shared Future (2020) Department of an Taoiseach association_en.pdf (oireachtas.ie)

⁴ Slaintecare Action Plan (2019) Department of Health

NEUROREHABILITATION SERVICES IN IRELAND

Over 800,000 Irish people are estimated to live with a neurological condition⁵ 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 Organisation⁶.

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 communities⁷

Neurorehabilitation services in Ireland are completely underdeveloped and under resourced 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.

Neurorehabilitation is critical for long term recovery from neurological 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.

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

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. Less than one in ten adult victims of major trauma in Ireland are discharged to specialist rehabilitation services⁸. The most recent report released by the National Office for Clinical Audit and focusing on paediatric trauma⁹ showed that only 1% of children were discharged to rehabilitation services from the acute hospital.

- 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 access to rehabilitative supports.

Findings from the Neurological Alliance of Ireland recently published report on Neurology Services¹⁰ showed that access to neurorehabilitation services has actually worsened over the five years 2015-2020, during which Ireland ratified the UNCRPD.

Neurology services represent a major source of referrals to neurorehabilitation services. The Neurological Alliance of Ireland surveyed neurology centres nationwide in 2015 and again in 2020 in relation to their access to inpatient and community neurorehabilitation services for their patients. Four of ten neurology centres surveyed reported lower levels of access to both inpatient and community neurorehabilitation in 2020 than they had in 2015 while all centres reported limited, very limited or no access to these services.

⁵ Strategic Review of Neurology and Neurophysiology Services in Ireland (2007) National Hospitals Office

⁶ 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

⁷ 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>

CONTENT OF THE DRAFT INITIAL STATE REPORT: ARTICLE 26

The following section reproduces the content in the Draft Initial State report¹¹ and provides a commentary on the actual situation in practice based on the experience of the Neurological Alliance of Ireland and its member organisations.

1. Implementation of the National Neurorehabilitation Strategy

Draft State Report Page 46: The National Strategy & Policy for the Provision of Neurorehabilitation Services in Ireland outlines a framework for the provision of rehabilitation services. An Implementation Framework for the Strategy, covering 2019-2021 sets out the implementation process. The Strategy commits to developing accessible services based on clinically assessed need. People presenting with neurological conditions including acquired brain injury are included in the recommended scope for local specialist inpatient neurorehabilitation units.

The Situation in Practice

The three-year implementation framework for the National Neurorehabilitation Strategy (2019-

2021)¹² is due to come to an end in December 2021. The framework committed to putting in place nine community neurorehabilitation teams nationwide by the end of 2021, one within each of the nine Community Health Organisation administrative areas (CHOs). To date (March 2021) only two have been funded, both in the East of the country, despite the lack of services across the entire rest of the country.

2. Establishment of a National Steering Group for Implementation of the National Neurorehabilitation Strategy

Draft State Report Page 46: A National Steering Group was established in 2017 as a governance structure to advance implementation of the Strategy and provide guidance and support to the local implementation teams developed in each health area

The Situation in Practice

The National Steering group has held only three meetings since the Implementation Framework was published in February 2019. The three-

year implementation framework for the Neurorehabilitation Strategy comes to an end in less than nine months (December 2021), despite this the group has not yet held a meeting this year (March 2021) and no upcoming meetings have been scheduled for 2021.

3. Redevelopment of the National Neurorehabilitation Hospital

Draft State Report Page 46: Construction of a new National Rehabilitation Hospital (NRH) has been undertaken and the hospital opened in 2020. Phase One of the development includes a fit for purpose ward accommodation block (120 single ensuite rooms) with integrated therapy spaces, a new Sports Hall, a hydrotherapy unit as well as clinical and ancillary spaces. It will enhance the environment for patients and contribute towards achieving optimum outcomes from their Rehabilitation Programme. It will enable staff to deliver services in a new and innovative environment designed specifically around patient needs.

The Situation in Practice

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 acute hospitals. The three-year implementation framework for the

⁸ Major Trauma Audit National Report (2018) National Office of Clinical Audit

⁹ Major Trauma Audit Paediatric Report (2021) National Office of Clinical Audit

¹⁰ Resourcing of Neurology Services in Ireland Five Years on (2015-2020) Key Findings from the Neurological Alliance of Ireland 2020 Survey of Neurology Services (March 2021) Neurological Alliance of Ireland

¹¹ Initial Report Under the Convention on the Rights of People with Disabilities (December 2021) Department of Children, Equality, Disability, Integration & Youth

¹² National Policy & Strategy for the Provision of Neurorehabilitation Services in Ireland: From Theory to Practice. Implementation Plan 2019-2021 (February 2019) Health Services Executive

CONTENT OF THE DRAFT INITIAL STATE REPORT: ARTICLE 26

National Neurorehabilitation Strategy (2019-2021) 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.

RECOMMENDATIONS: CALL FOR REVISION OF THE DRAFT REPORT

Ireland continues to lag far behind in meeting its responsibilities under the UNCRPD to provide 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 the current reporting on Article 26 in the Draft Report to be revised to reflect the significant work that must be done to implement existing policy and to provide a clear timeframe for implementation of the Neurorehabilitation Strategy through successive Implementation Frameworks beyond 2021.

The HSE Service Plan 2021¹³ commits to a “review of the Neurorehabilitation Services in Ireland From Theory to Action Implementation Plan 2019-2021 and develop the framework for 2022-2024”

NAI is calling for the following wording to be inserted into the Draft Report under Article 26

“Ireland recognises the ongoing gaps in neurorehabilitation service provision and the significant work that remains to be done to implement existing policy in this area. Successive Implementation Frameworks for the National Neurorehabilitation Strategy will be developed 2022-2024 and beyond with a commitment to providing the full

range of hospital and community-based neurorehabilitation services in line with existing policy”.

The revised wording in the report must be matched with a real commitment in practice to proper investment in neurorehabilitation services in order to ensure the implementation of the Neurorehabilitation Strategy: a commitment in both the current Programme for Government and the Slaintecare Action Plan.

¹³ *National Service Plan 2021 (2021) Health Services Executive*

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.

Further Information

For further information on any aspect of this submission please contact the NAI Executive Director Magdalen Rogers at mrogers@nai.ie or 01 8724120.

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

Neurology Support Centre

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

Neurological Alliance of Ireland
Coleraine House,
Coleraine Street,
Dublin 7
CHY 14889

www.nai.ie
01 8724120

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