



**An Roinn Leanaí, Comhionannais,
Míchumais, Lánpháirtíochta agus Óige**
Department of Children, Equality,
Disability, Integration and Youth



Údarás Náisiúnta Míchumais
National Disability Authority

National Disability Strategy call for written submissions

Please answer the questions below and submit to nda-events@nda.ie by **Friday 02 February 2024**. We ask that you please adhere to the word counts provided. An A4 page with single spaced text font 12 is between 400 and 500 words.

You can also post your submission to:

NDS Consultation,

National Disability Authority,

25 Clyde Road,

Dublin 4.

About you

Please respond to one of the options below.

I am responding as:

- A representative of a Disabled Persons Organisation
If yes, please specify your name and the name of the organisation:
- A representative of another disability organisation
If yes, please specify your name and the name of the organisation:
Magdalen Rogers, Executive Director Neurological Alliance of Ireland
For any further information on this submission please feel free to contact me mrogers@nai.ie
- An individual with a disability
If yes, please provide your name (your name will not be included in the consultation summary):
- An individual who is a carer
If yes, please provide your name (your name will not be included in the consultation summary):
- Other
Please specify:

Questions

The vision of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), which Ireland has ratified, is that disabled people can exercise their human rights like everyone else in society and have an equal opportunity to live their lives with dignity, respect, and equality.

- **Question 1:** What changes do you see as important to ensure that disabled people in Ireland are fully included in society in line with the vision of the UNCRPD? (Maximum 500 words)

Over 800,000 people in Ireland are living with a neurological condition affecting the brain and spinal cord. It is estimated that 2% are significantly disabled by their condition on a daily basis¹. In 2016, neurological disorders were the leading cause of global DALYs, responsible for 276 million DALYs (Disability Adjusted Life Years), comprising 11.6% of DALYs for all diseases worldwide². Access to neurorehabilitation is vital to promote recovery and prevent disability for people with neurological conditions. Article 26³ of the UNCRPD recognises the crucial importance of rehabilitation to enabling people with disabilities, including neurodisability, to achieve their full potential.

Access to neurorehabilitation services for children and adults with a neurodisability in Ireland is significantly underdeveloped and fragmented and, in contrast to the goals of the UNCRPD, is characterised by significant geographic inequities⁴. The National Policy and Strategy for the Provision of Neurorehabilitation Services in Ireland notes “significant underdevelopment and fragmentation of neurorehabilitation services in Ireland”.

The dearth of neurorehabilitation services for adults with neurological conditions impacts on the patient journey at all stages: from acute to post acute and long term rehabilitation in the community. Only one in ten adult major trauma patients were

¹ Strategy Review of Neurology and Neurophysiology Services in Ireland (2007) National Hospitals Office Health Services Executive

² Carroll (2019) The Global Burden of Neurological Disorders Lancet March 14th 2019
[https://www.thelancet.com/journals/laneur/article/PIIS1474-4422\(19\)30029-8/fulltext](https://www.thelancet.com/journals/laneur/article/PIIS1474-4422(19)30029-8/fulltext)

³ Article 26³: States Parties shall take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life. To that end, States Parties shall organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services.

⁴ National Policy and Strategy for the Provision of Neurorehabilitation Services in Ireland (2011) Department of Health

discharged to a rehabilitation facility between 2019 and 2020⁵. To quote directly from the Major Trauma Audit National Report “it is of concern that so few (10%) of patients continued to receive rehabilitation in an inpatient facility”.

The three year Implementation Framework for the National Neurorehabilitation Strategy⁶ notes that neurorehabilitation services for adults are characterised long waiting lists for specialist rehabilitation services, limited access to specialist rehabilitation services for those who need them and a dearth of community based specialist rehabilitation services and support services within the community to manage the longer term needs of people with neurological conditions.

Access to specialist neurorehabilitation for children is arguably even more limited in an Irish context. The National Model of Care for Paediatric Healthcare outlines the need for dedicated acute, post acute and specialist community neurorehabilitation services. In its submission to the Draft Initial State Report on the UNCRPD⁷, the Neurological Alliance of Ireland noted that Ireland continues to lag far behind in meeting its responsibilities under the UNCRPD to provide rehabilitation services to people with acquired neurodisabilities. The implementation of existing policy in this area, through the rollout of properly resourced neurorehabilitation services throughout the country, is key to ensuring that people living with a neurodisability are supported to achieve their full potential in society.

- **Question 2: What needs to happen for these changes to be achieved? (Maximum 500 words)**

Access to neurorehabilitation services is critical to enabling adults and children living with an acquired neurodisability to achieve their potential and be fully included in Irish society in line with the vision of the UNCRPD.

It is vital that the commitments to the development of neurorehabilitation services outlined in the Action Plan for Disability Services 2024-2026⁸ are actioned within the timeframe of the plan. The Action plan commits to the setting up of an 18WTE community neurorehabilitation team in each of the six health regions now being established. In addition, the plan outlines a commitment to identifying level 2 inpatient rehabilitation sites within each of the managed clinical networks for the delivery of specialist rehabilitation services.

These managed networks will co-ordinate the provision of acute and post acute inpatient neurorehabilitation services as well as specialist neurorehabilitation teams in

⁵ Major Trauma Audit National Report (2020) National Office of Clinical Audit

⁶ From Theory to Action: Implementation Framework National Policy & Strategy for the Provision of Neurorehabilitation Services in Ireland 2019-2021 (2019) Health Services Executive

⁷ Response to the Draft State Report on the Implementation of the UNCRPD (March 2021) Neurological Alliance of Ireland

⁸ Action Plan for Disability Services 2024 2026 (December 2023) Department of Children, Equality, Integration and Youth

the community providing up to twelve weeks of short term intensive rehabilitation input. The Implementation Framework also outlines the need for long term specialist neurorehabilitation services in the community to include residential rehabilitation, transitional and home-based rehabilitation, day rehabilitation services, vocational rehabilitation and family supports.

A framework of specialist neurorehabilitation services for children is outlined in the National Model of Care for Paediatric Healthcare in Ireland. This recommends the development of acute and post acute paediatric specialist rehabilitation services together with long term supports in the community. A report published in 2023 highlighted the need for specialist services in the community for children with acquired brain injury, outlining that existing primary care and children's network disability teams struggle to meet the complex needs of these children for specialist long term neurorehabilitation in the community⁹.

Meeting Ireland's commitments under Article 26 to provide access to rehabilitation for people with a neurodisability will require effective engagement with the voluntary disability organisations which play a critical role in designing and delivering long term supports to people with neurological conditions in the community. A nationwide survey of over 40 voluntary organisations carried out in 2022¹⁰ found that these organisations were providing almost one hundred unique services and supports to people with neurological conditions living in the community, ranging from therapeutic and clinical supports supported living, respite and accessibility supports through to vocational rehabilitation and training/employment services as well as family support and education.

These organisations play a critical role in supporting the long term needs of people with neurological conditions to achieve their full potential in line with the vision of the UNCRPD.

There is a consistent and growing body of evidence highlighting the importance of timely access to appropriate neurorehabilitation to positive outcomes for people with a neurological condition.

Changing the landscape for people with neurological conditions in Ireland, in order to achieve the vision outlined in the UNCRPD, requires an effective commitment to resourcing the implementation of existing policy to ensure access to neurorehabilitation services for all those who need them.

⁹ A National Model of Care for Paediatric Healthcare Services In Ireland (Chapter 4 Specialist Rehabilitation) RCPI & Clinical Strategy & Programmes Division Health Services Executive

¹⁰ Mapping Existing Services Provided by the Voluntary Sector for People Living with Neurological Disabilities/Conditions in the Community (April 2022) Disability Federation of Ireland, Neurological Alliance of Ireland, Health Services Executive

https://www.disability-federation.ie/assets/files/pdf/neuro_mapping_project_report_19_april_2023.pdf

- **Question 3:** What would a successfully implemented strategy look like? For example, how do you think life should have improved for disabled people in Ireland at the end of a five-year strategy? * (Maximum 500 words)

* Please note that the length of the strategy has not yet been confirmed.

A successfully implemented National Disability Strategy would ensure that Ireland meets its commitments under the UNCRPD under Article 26 by make full provision for the long term needs of people living with a neurological disability throughout Ireland.

Some progress has been made in the provision of neurorehabilitation services with funding to support the establishment of community neurorehabilitation teams in six of the nine Community Health Organisation (CHO) administrative areas between 2020 and 2023. The size of the planned teams was also expanded from 5 WTE to 13 WTE in order to transition to the level of staffing recommended for these teams within the Model of Care for Specialist Rehabilitation Medicine in Ireland. Investment was also announced in 2023 for two specialist teams in the community for children with acquired brain injury. j

This progress, while warmly welcomed, still leaves a considerable gap to be addressed in the provision of neurorehabilitation services in the community. The 2019 Implementation Framework for the National Neurorehabilitation Strategy outlines a service framework for community neurorehabilitation services that should include (a) Community Neuro-Rehabilitation Teams (CNRT) Community Neuro-Rehabilitation teams providing short term intensive rehabilitation input (up to 12 weeks) AND (b) specialist community neuro-rehabilitation services (long term rehabilitation input beyond 12 weeks) to include residential rehabilitation, transitional rehabilitation, home based/community rehabilitation including intensive home care packages, day and vocational rehabilitation and family supports. Longer term (beyond 12 weeks) neurorehabilitation services in the community are critical to maintain the gains and meet the needs of people with neurological conditions beyond the twelve week period of intervention of specialist community neurorehabilitation teams.

The National Neurorehabilitation Strategy is focused on the needs of adults over eighteen years with a recent and welcome broadening of scope to address the neurorehabilitation needs of people over the age of sixty five. However there is a critical need to develop neurorehabilitation services to meet the needs of children with conditions such as acquired brain injury and also to develop a pathway of transitional care for children moving from paediatric to adult services.

A successfully implemented National Disability Strategy would ensure that the needs of the person with a neurological disability are met from the time of diagnosis/onset through to their need for rehabilitation and long term support to enable them to live well with their condition. During a five year National Disability Strategy, the priority for both adults and children with an acquired neurological disability should be to put in place a national framework of neurorehabilitation services.

- **Question 4:** If you have any other views that are relevant to the new National Disability Strategy please tell us? (Maximum 300 words)

For further information on any aspect of this submission, please contact Magdalen Rogers, Executive Director of the Neurological Alliance of Ireland
mrogers@nai.ie

The Neurological Alliance of Ireland (NAI) brings together 30 non-profit organisations to advocate for the rights of 800,000 people in Ireland living with a neurological condition.

Neurological conditions affect the brain and spinal cord. They are the leading cause of disability throughout the world and include many common conditions such as stroke, dementia, migraine, epilepsy and acquired brain injury as well as rare and genetic conditions.

Founded in 2003, the NAI advocates for the development of quality services for people with neurological conditions. Our campaigns are rooted in the experience of our members and the people and families with whom they work. We provide a united and expert voice on neurological care through advocacy, policy development, and awareness raising.

Further information is available at www.nai.ie,