



Opening Statement to the Oireachtas Committee on Disability Matters

2<sup>nd</sup> October 2024

On behalf of the Neurological Alliance of Ireland, the national umbrella for over 30 neurological charities throughout Ireland, I would like to thank the Chair and members of the Committee for their joint invitation today to the Neurological Alliance of Ireland and MS Ireland, together with NAI members An Saol, to discuss Ireland's response to the rehabilitation needs of people living with neurological conditions, in the context of the commitment to rehabilitation as a right under Article 26 of the UNCRPD.

Neurorehabilitation refers to the treatment provided to individuals after experiencing a neurological injury, illness, or diagnosis of a neurological condition. This description does not adequately convey the fundamental hope and potential that neurorehabilitation gives to people with neurological conditions. It can be the difference between returning to employment, living independently, retaining or recovering the ability to do everyday tasks and living a full life after a neurological diagnosis.

Unfortunately in Ireland, access to neurorehabilitation can be a lottery. Neurorehabilitation services are not available equally across the country. Many parts of Ireland remain significantly underserved when it comes to neurorehabilitation services and the findings of a HSE report on inpatient rehabilitation published just last week further highlights the stark gaps in neurorehabilitation services.

Article 26 of the UNCRPD is about putting people living with a disability at the centre of their rehabilitative and habilitative care. It's offering a choice, to prevent crises, and to support people living with a disability in the way they want to be supported.

The gold standard of this implementation is already being put in place by our voluntary sector providers, through the 2019 Neurorehabilitation Strategy commitment to develop long term neurorehabilitation services in the community.

As an example, services provided by MS Ireland include Community Worker Service, Wellness and Symptom Management Programmes, Exercise and Physiotherapy Programmes open to people with a range of neurological conditions and respite care through the MS Care Centre.

We will highlight other examples throughout our presentation where NAI member organisations, including our members An Saol who are also joining us today, are providing critical services, in line with the long term needs identified in the Neurorehabilitation Strategy, in a range of areas such as residential care, vocational rehabilitation, day services and family and carer supports.

The well publicised challenges facing Section 39 voluntary providers of funding shortfalls, staff recruitment and retention difficulties and increasing costs of delivering services represent a serious ongoing threat to the continuation of these services. Much more needs to be done to

properly invest in, sustain and develop these vital community supports so they are available to everyone who needs them.

The 2019-2021 Implementation Framework for the National Neurorehabilitation Strategy focused on three key deliverables: the development of community neurorehabilitation teams, the delivery of long term community neurorehabilitation services and the development of inpatient neurorehabilitation services.

There is no doubt that welcome progress has been made in recent years in delivering on some aspects of the Strategy. In particular, the Minister for Disability Anne Rabbitte has invested significantly in the rollout of community neurorehabilitation teams in line with the Programme for Government commitment to implement the Neurorehabilitation Strategy. She has, in addition, commissioned pioneering research to understand the challenges facing both service users and service providers in accessing and delivering neurorehabilitation services in the community. This Neuromapping Project, a joint collaboration between the Neurological Alliance of Ireland, Disability Federation of Ireland and the HSE will issue a report to be launched by the Minister in the coming weeks.

It is clear however that much more still remains to be done if Ireland is to meet its obligations to people with neurological conditions under Article 26 through the full implementation of the National Neurorehabilitation Strategy.

The National Neurorehabilitation Strategy provides a much needed framework and impetus for developing neurorehabilitation services.

We know what needs to be done to make Article 26 a lived reality for people with neurological conditions and their families throughout Ireland.

We have acknowledged the meaningful progress that has been made, through the commitment of Minister Anne Rabbitte, and through the work of our fellow members of the National Steering Group responsible for implementing the Neurorehabilitation Strategy. It is only by ensuring that everyone who needs neurorehabilitation, regardless of age, condition or where they live, that we can meet our obligations under the UNCRPD to the thousands of people throughout Ireland living with a neurological condition.

Our presentation today focuses on the neurorehabilitation needs of adults over 18, the age cohort for the National Neurorehabilitation Strategy. We are aware that services for children with neurological conditions are if anything in even more critical need of development. This issue warrants a discussion beyond the time we have available today, NAI would be happy to provide support and information to the Committee in convening a future meeting given the importance of this issue to children and families all across Ireland.

We once again thank the Committee for their interest in the issue of access to neurorehabilitation services and we request their support in the following:

- supporting the Neurological Alliance of Ireland and its members in their call for full implementation of the Neurorehabilitation Strategy, including seeking a sustainable provision of the long term services and supports they provide in the community, and ensuring these supports are available to everyone who needs them.

