A decorative graphic on the left side of the page consists of a series of overlapping, semi-transparent green ovals. The ovals are arranged in a horizontal line that tapers from left to right, creating a sense of depth and movement. The colors range from a light, pale green to a vibrant, saturated green.

PRE-BUDGET SUBMISSION  
2023

AUGUST 2022

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## CONTEXT: INVESTMENT IN NEUROLOGICAL CARE URGENTLY NEEDED TO ADDRESS THE IMPACT OF COVID19

The Neurological Alliance of Ireland, the national umbrella for over thirty neurological charities, is calling for €3.3m in funding for neurological care services in this year's Budget:

- **Appoint 20 additional nurse specialists across adult neurology services €1.5m**
- **Fully resource at least four of the seven required community neurorehabilitation teams €1.8m**

Over 800,000<sup>1</sup> Irish people are living with neurological conditions affecting the brain and spinal cord. The World Health Organisation published a ten year framework<sup>2</sup> for neurological conditions in May this year, highlighting that one in three of us will experience a neurological condition at some point in our lifetime. According to the WHO, neurological conditions now represent the leading cause of disability adjusted life years and second leading cause of death worldwide.

However, in a year where neurology has become a recognised global health priority by the WHO, the over 800,000 Irish people living with neurological conditions continue to experience serious challenges in accessing vital services, a situation that has worsened during the pandemic.

Throughout Europe, the COVID19 pandemic has had a serious impact on access to care and treatment for people with neurological conditions<sup>3,4,5</sup>. Here in Ireland,

this problem has been compounded by decades of underinvestment in neurological care services. Under-resourced services, already operating at capacity pre-COVID, did not have the resources to respond to the pent-up demand caused by the curtailment of services and redeployment of staff during the pandemic.

**Neurology waiting lists now stand at over 24,000<sup>6</sup>, almost a 20% increase over five years.** Of serious concern to the Neurological Alliance of Ireland and its members is the growth in **the numbers of people waiting more than 18 months across this period, which has nearly doubled from 4,040 in 2018 to 7,636 in 2022.** This is unacceptable for individuals and families facing the possibility of a life changing diagnosis.

**Access to neurorehabilitation services has also been severely impacted by the pandemic<sup>7</sup> due to the pent-up demand for rehabilitation and the inability of a completely underdeveloped and under-resourced service to respond to the backlog.**

There has been a critical lack of progress in implementing the three-year framework for neurorehabilitation services 2019-2021<sup>8</sup>, despite a commitment to implementation in the current Programme for Government<sup>9</sup> and the Slaintecare Action Plan<sup>10</sup>. Seven of the nine CHOs around the country have no community neurorehabilitation teams, including the two CHOs where the major national trauma centres are located. **The framework committed to establishing a community neurorehabilitation team within each CHO but no additional teams were put in place across the three-year implementation period.**

<sup>1</sup> Strategic Review of Neurology and Neurophysiology Services in Ireland (2007) Report Commissioned by the National Hospitals Office, HSE

<sup>2</sup> Intersectoral Global Action Plan on Neurological Disorders and Epilepsy 2022-2031 (2022) World Health Organisation

<sup>3</sup> Chahnez Charfi Triki et al (2021) Global survey on disruption and mitigation of neurological services during COVID19: the perspective of global international neurological patients and scientific associations. Journal of Neurology (2021) June 11; 1-13

<sup>4</sup> Bhaskar et al (2020) Chronic Neurology in COVID19 Era (2020) Front Neurol (2020) 11:664

<sup>5</sup> Lessons Learned from the COVID19 pandemic: Priorities in care for people with neurological conditions after the pandemic (2020) National Neurology Advisory Group UK

<sup>6</sup> Website of the National Treatment Purchase Fund www.ntpf.ie (OPD waiting lists by specialty May 2022)

<sup>7</sup> Rehabilitation in the Wake of COVID19: A phoenix from the ashes (2020) British Society of Rehabilitation Medicine

<sup>8</sup> 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

<sup>9</sup> Programme for Government: Our Shared Future (October 2020) Government of Ireland Publications

<sup>10</sup> Slaintecare Action Plan (2019) Department of Health

# ASK 1: FUNDING FOR TWENTY NURSE SPECIALISTS IN ADULT NEUROLOGY SERVICES €1.5M

A National Audit of Neurology Centres<sup>11</sup>, carried out by the Neurological Alliance of Ireland in late 2020, found that staffing across multidisciplinary teams in the ten neurology centres across the country had remained static or even declined in some specialities over the five years between 2015 and 2020. This is despite an almost 50% increase in outpatient activity in neurology services across the same period. Neurology services are now receiving record numbers of referrals, with the same level of resources that were in place five years ago. The failure of resourcing to keep pace with increased demand means that neurology waiting lists now stand at over 24,000<sup>12</sup>, almost a 20% increase over five years. Of serious concern to the Neurological Alliance of Ireland and its members is the growth in the numbers of people waiting more than 18 months across this period, which has nearly doubled from 4040 in 2018 to 7636 in 2022. This is unacceptable for individuals and families facing the possibility of a life changing diagnosis.

Nurse specialists are vital to the care of people with neurological conditions: despite this one fifth of people with Parkinson’s disease across Ireland, for example, have no access to a nurse specialist and Ireland has less than half the recommended number of specialist nurses for multiple sclerosis. There are no nurse specialists for a range of disabling neurological conditions including Huntington’s disease, and adults with spina bifida and muscular dystrophy. Nurse specialists are also important in tackling waiting lists: a pilot headache pathway across three Irish hospitals found that nurse specialists play a vital role in reducing presentations to hospital, including reducing the burden on neurology services . The Neurological Alliance of Ireland are calling for funding for twenty specialist nurses in adult neurology services in Budget 2023 as part of a multiannual plan to tackle the shortfall of one hundred specialist neurology nurses in line with the Model of Care for Neurology .

**Table 1: International and HSE Model of Care Recommendations for Nurse Specialist Staffing in Neurology**

Disease Area	Recommendation	No. of Nurses	Source
Multiple Sclerosos	1 nurse per 315 patients	29	<i>MS Specialist Nursing in the UK (2018) Results from the 2018 MS Nurse Mapping Survey</i>
Headache	1 nurse per 140,000 population	36	<i>Neurology Model of Care for Ireland (2016) page 164</i>
Epilepsy	1 nurse per 140,000 population	36	<i>Epilepsy Model of Care for Ireland (2016) page 22</i>
Parkinson’s Disease	1 nurse per 300 patients	31	<i>NICE Guidelines and Neurology Model of Care for Ireland (2016)</i>
Rare Diseases	1 nurse per 500,000 population	10	<i>Local Adult Neurology Services for the Next Decade (Royal College of Physians, Association of British Neurologists June 2011)</i>
Total		142	

Source: Neurological Alliance of Ireland Patients Deserve Better Campaign 2021

<sup>11</sup> Resourcing of Neurology Services in Ireland Five Years On 2015-2020 (2021) Neurological Alliance of Ireland

<sup>12</sup> Website of the National Treatment Purchase Fund www.ntpf.ie (OPD waiting lists by specialty May 2022)

## ASK 1: FUNDING FOR TWENTY NURSE SPECIALISTS IN ADULT NEUROLOGY SERVICES €1.5M *Continued*

Nurse specialists are vital to the care of people with neurological conditions<sup>13</sup>. However, only one fifth of people with Parkinson's disease have access to a nurse specialist, while Ireland has less than half the number of recommended specialist nurses for people with multiple sclerosis. There are no nurse specialists for a range of disabling neurological conditions including Huntington's disease, and adults with spina bifida and muscular dystrophy. Nurse specialists are also important in tackling waiting lists: a pilot headache pathway across three Irish hospitals found that nurse specialists play a vital role in reducing presentations to hospital, including reducing the burden on neurology services<sup>14</sup>.

**The Neurological Alliance of Ireland are calling for funding for twenty specialist nurses in adult neurology services in Budget 2023 as part of a multi-annual plan to tackle the shortfall of one hundred specialist neurology nurses in line with the Model of Care for Neurology<sup>15</sup>.**

<sup>13</sup> Christodoulou M (2012) Neurological Nurse Specialists: A vital resource under threat. The Lancet Neurology March 2012: Vol 11 Issue 3 P210-211

<sup>14</sup> Press release Department of Health April 2022 <https://www.gov.ie/en/press-release/e5ee1-minister-donnely-welcomes-approval-of-new-clinical-pathway-for-headache/>

<sup>15</sup> Model of Care for Neurology Services in Ireland (2018) HSE Clinical Strategy and Programmes

## ASK 2: FUNDING TO FULLY RESOURCE AT LEAST FOUR OF THE SEVEN REQUIRED COMMUNITY NEUROREHABILITATION TEAMS €1.8M

The current Programme for Government states a commitment to implementing the National Neurorehabilitation Strategy which was developed in order to provide people presenting with neurorehabilitation needs access to a range of quality services and supports so as to enhance their quality of life and wellbeing.

Access to neurorehabilitation services in Ireland has been seriously impacted by the COVID19 pandemic. This is due to a number of factors which have caused a pent-up demand for rehabilitation on top of an already under-resourced service. In a paper released in August 2020, the National Clinical Programme for Rehabilitation Medicine highlighted the impact of COVID19 in generating a significant backlog in rehabilitation demand as patients missed out on rehabilitation during the pandemic due to (i) early discharge from acute hospitals (ii) early discharge home instead of a post-acute rehabilitation facility and (iii) limited services in the community discontinued due to redeployment of staff in the community.

In addition, the Clinical Programme highlighted the need for specialist rehabilitation among those affected by the coronavirus itself: noting that this will place a significant burden on already under-resourced services. *“Ireland is particularly vulnerable in relation to its capacity to serve an influx of persons re-quiring specialist rehabilitation interventions as a result of COVID19 “National Clinical Programme for Rehabilitation Medicine August 2020”<sup>16</sup>*

Ireland continues to have among the most underdeveloped neurorehabilitation services throughout Europe with the lowest numbers of consultants in rehabilitation medicine and a significant dearth of inpatient and community neurorehabilitation services<sup>17</sup>. The Department of Health Capacity Review of Disability Services, published in 2021, points to the “major shortfall in timely access to neurorehabilitation services”.

The serious delays and lack of progress in implementing the 2019-2021 framework for the National Neurorehabilitation Strategy, a commitment in the current Programme for Government and the Slaintecare Action Plan, were highlighted by the NAI in March this year to the Oireachtas Committee on Health<sup>18</sup>.

A submission by the Neurological Alliance of Ireland<sup>19</sup> in response to the first State report on UNCRPD<sup>20</sup> highlighted that Ireland is failing in its undertaking to provide comprehensive rehabilitation services for people with a neurodisability under article 26 of the UNCRPD noting that, “the lack of commitment to implementing existing policy on neurorehabilitation represents a clear failure on the part of this country to its citizens with a neurodisability”. The Intersectoral Global Action Plan on Neurological Conditions and Epilepsy 2022-2031, published by the World Health Organisation in May this year calls on member countries to “ensure equitable access to rehabilitation for disability associated with neurological conditions”.

<sup>16</sup> Rehabilitation Response and Intervention Considerations in the Republic of Ireland during the COVID19 pandemic (August 2020) National Clinical Programme for Rehabilitation Medicine: Clinical Strategy and Programmes HSE

<sup>17</sup> National Policy & Strategy for the Provision of Neurorehabilitation Services in Ireland (2011) Department of Health

<sup>18</sup> Opening Statement to the Oireachtas Committee on Health (March 30th 2022) Neurological Alliance of Ireland

<sup>19</sup> Response to the Draft Initial State Report UNCRPD (April 2021) Neurological Alliance of Ireland

<sup>20</sup> Initial Report on the Convention on the Rights of People with Disabilities (Draft for Consultation March 2021) Department of Health

## ASK 2: FUNDING TO FULLY RESOURCE AT LEAST FOUR OF THE SEVEN REQUIRED COMMUNITY NEUROREHABILITATION TEAMS €1.8M *Continued*

One of the key recommendations of the 2019-2021 framework for the National Neurorehabilitation Strategy is the establishment of a network of nine community neurorehabilitation teams around the country, one in each CHO (Community Health Organisation) area. These multidisciplinary teams provide vital care to support recovery and prevent disability for people with neurological conditions including acquired brain injury, stroke, multiple sclerosis and Parkinson's disease. No additional teams were established over the three year implementation period 2019-2021, which means that seven of the nine CHO's nationwide continue to have no community neurorehabilitation team.

The National Trauma Strategy recommends that "the HSE should ensure co-ordinated development of regional and community rehabilitation services, including appropriately resourced and skilled community rehabilitation teams".

**It is unacceptable that the CHO areas which are the sites for the two major national trauma centres continue to lack a dedicated community neurorehabilitation team.**

The Neurological Alliance of Ireland is calling for funding in the forthcoming budget for at least four of the seven required community neurorehabilitation teams in 2023 and a clear commitment to fund the remaining three teams in 2024. This investment must be prioritised in order to address the failure to put these teams in place during 2019-2021 in line with the Programme for Government commitment to implement the National Neurorehabilitation Strategy.

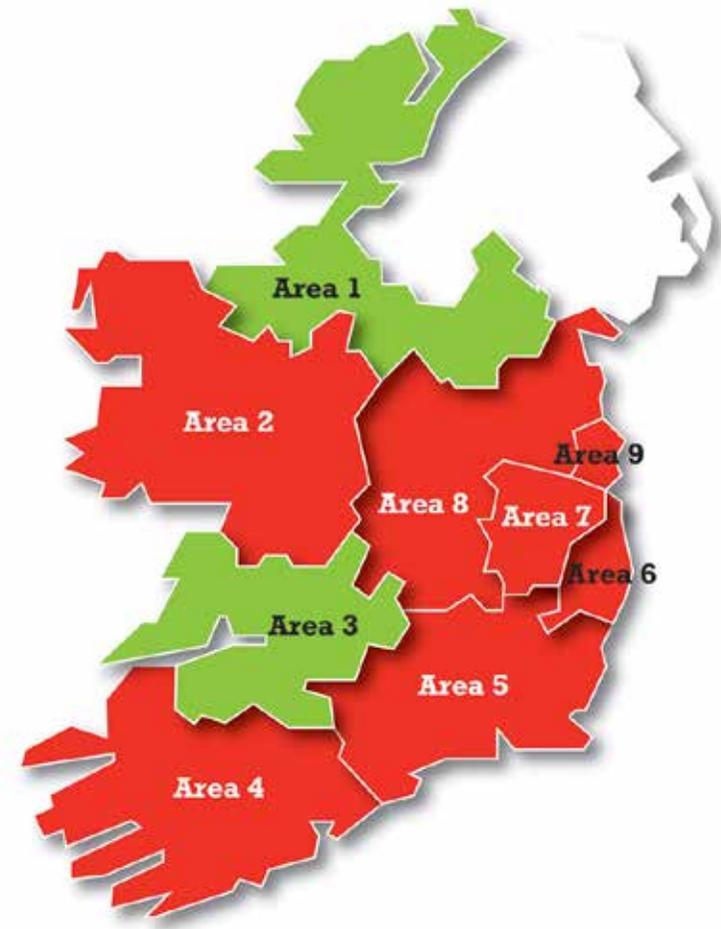


Fig (1) MAP of Community Health Organisation (CHO) areas that have a dedicated Community Neurorehabilitation Team in Place (Red indicates the CHO areas that have no dedicated teams)

## NAI CALL FOR A COMMITMENT TO RESOURCING DISABILITY SERVICES AND OTHER WIDER SUPPORT FOR PEOPLE LIVING WITH NEUROLOGICAL CONDITIONS AND THEIR FAMILIES

In May this year, the World Health organisation published a ten year framework for neurological disorders and epilepsy: recognising that “the ongoing COVID19 pandemic highlights the relevance of neurology to global public health” and calling on member countries to “improve access to care and treatment for people already living with neurological disorders”.

The number of people diagnosed with a neurological condition across the developed world, including in Ireland, will continue to increase due to an ageing demographic and there is evidence that the growth in neurodegenerative conditions may be exacerbated by the COVID19 pandemic<sup>21</sup>.

The Neurological Alliance, as a broad coalition of neurological charities, recognises the critical importance of developing and resourcing services across

the spectrum of neurological disease and neuro-disability to overcome decades of underinvestment. We are therefore supporting the pre-budget submissions of our individual member organisations listed below.

We also recognise that people with neurological conditions are members of a broader community of citizens in Ireland living with a disability, and that they and their family members are impacted growing waiting lists for disability services, gaps in care and lack of adequate supports around home care.

We are therefore supporting the asks outlined in the pre-budget submissions of the Disability Federation of Ireland, Rare Disease Ireland and Family Carers Ireland as the most vulnerable in our society now face a cost of living crisis after two years of overwhelming challenge due to the COVID19 pandemic.

## FURTHER INFORMATION

For further information on any aspect of this submission, contact Magdalen Rogers, Executive Director Neurological Alliance of Ireland at [mrogers@nai.ie](mailto:mrogers@nai.ie) or 01 8724120

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<sup>21</sup> The neurological consequences of COVID19 (June 2020) Lancet (2020) Vol 19 Issue 6 Page 471

## MEMBER ORGANISATIONS OF THE NEUROLOGICAL ALLIANCE OF IRELAND

*Acquired Brain injury Ireland*

*Alzheimer Society of Ireland*

*An Saol*

*Aphasia Ireland*

*Ataxia Foundation Ireland*

*Aware*

*Bloomfield Health Services*

*Cheshire Ireland*

*Chronic Pain Ireland*

*Dystonia Ireland*

*Early Onset Parkinson's Disease Association  
(EOPD)*

*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*

*Peamount Healthcare*

*Polio Survivors Ireland*

*PSPA Ireland*

*Slanu Stroke Rehab*

*Spinal Injuries Ireland*

*Spina Bifida Hydrocephalus Ireland*

*The Rehab Group*

### **Associate Members**

*Brain Tumour Ireland*

*Syringomyelia Chiara Malformation  
Support Group*



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