

**THE NEUROLOGICAL ALLIANCE  
OF IRELAND IS CALLING FOR  
THE FOLLOWING INVESTMENT  
IN NEUROLOGICAL CARE IN THE  
UPCOMING BUDGET**



**NEUROLOGICAL  
ALLIANCE OF IRELAND  
PRE BUDGET SUBMISSION  
2021**

**THE NEUROLOGICAL  
ALLIANCE OF IRELAND IS THE NATIONAL  
COALITION ON NEUROLOGICAL CARE**

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Tuaithe agus Pobail  
Department of Rural and  
Community Development



## ISSUES

Funding crisis among not for profit providers of neurological care services

Increasing demand for neurorehabilitation services which were completely underdeveloped pre COVID-19

Increasing demand on neurology services already coping with their highest ever waiting lists pre COVID-19

The COVID-19 pandemic has unveiled major deficits in neurological care in Ireland at a time when these services are critically needed in the fight against COVID-19.

A significant percentage of people with COVID-19 have neurological symptoms, including increased risk of stroke and functional neurological problems. As our health system gears up for what may be a lengthy response to this pandemic, the need for investment in neurological care is now critical.

## ASKS

Establishment of a special fund to meet COVID-19 fundraised losses and elimination of deficits among Section 39 providers of neurodisability services, as called for by the Disability Action Coalition and other umbrella organisation.

Investment of €4.5m in neurorehabilitation services as a first step in meeting the commitment in the Programme for Government to implement the National Neurorehabilitation Strategy<sup>1</sup>

Investment of €3.3m in Neurology Services to address critical understaffing in neurology services leading to the highest ever waiting lists now exacerbated by the COVID-19 pandemic

## COVID-19 AND NEUROLOGICAL CARE

Over 800,000 Irish people are living with neurological conditions including dementia, stroke, epilepsy, acquired brain injury, multiple sclerosis and Parkinson's disease. The lack of investment in neurology and neurorehabilitation services and successive cuts to Section 39 providers meant that neurological care services were at breaking point pre COVID-19.

The serious immediate and long-term neurological consequences of COVID-19 are increasingly emerging with better understanding and

research into the pandemic<sup>2</sup>. The Neurological Alliance of Ireland's submission to the Oireachtas Committee on COVID-19 in July this year<sup>3</sup>, highlighted that the COVID-19 pandemic has unveiled major deficits in neurological care in Ireland at a time when these services are critically needed in the fight against COVID-19.

COVID-19 continues to have a significant impact on neurological care for the 800,000 Irish people living with neurological conditions.

# ISSUES 1

## FUNDING CRISIS AMONG NOT FOR PROFIT PROVIDERS OF NEUROLOGICAL CARE SERVICES

**The entire model of service provision in the community for people with neurological conditions in Ireland is critically reliant on not for profit neurological organisations and completely unsustainable if these organisations are forced to close or curtail their services.**

Not for profit organisations are integral and essential to the delivery of neurological care services in Ireland, providing services ranging from specialist nurses to neurorehabilitation services, respite, day services and residential care, helpline and counselling supports as well as raising vital funds for research into neurological conditions.

*“The vital importance of not for profit organisations in the delivery of everyday care for neurological illness in Ireland cannot be overstated, they contribute millions each year from fundraised income without which neurological care in this country could not be sustained” (Professor Orla Hardiman, Clinical Lead for Neurology, National Clinical Programme)*

Not for profit organisations responded rapidly and flexibly to the COVID-19 outbreak, moving their services online, designing innovative approaches to service provision and providing access to specialist advice, information and support for people with specific neurological conditions. A survey carried out by the Neurological Alliance in May 2020<sup>4</sup> showed an overwhelming reliance on neurological patient organisations as the most important source of condition-specific information and advice for people with neurological conditions and their carers in relation to COVID-19.

The impact of COVID-19 on public fundraising presents an immediate and serious threat to the future of these organisations and the services they provide. Section 39 organisations, already struggling with significant deficits pre COVID-19 have come under enormous pressure due to the collapse of public fundraising. A survey carried out by the Disability Federation of Ireland<sup>5</sup> of 20 disability service providers, including providers of neurodisability services, found that:

- 37% are concerned they won't be viable after six months
- 50% have laid off or are preparing to lay off staff
- Essential services are threatened for 55% of organisations due to the loss of fundraised income
- The sample of 20 organisations expect a potential fundraising loss of over €7 million in 2020. The sector-wide loss will be substantially higher.

Neurodisability service providers, in addition to the loss of fundraised income, are now facing additional costs associated with protective equipment, staff training, cleaning etc which will have an additional impact on their budgets.

## ASKS 1

### Establishment of a special fund to meet COVID-19 fundraised losses and elimination of deficits among Section 39 providers of neurodisability services, as called for by the Disability Action Coalition and other umbrella organisations<sup>6</sup>

The Neurological Alliance of Ireland is supporting the calls of the Disability Action Coalition, the Disability Federation of Ireland and other representative groups for a special fund to protect charities and services most at risk as well as a guarantee that HSE funding is secured, without any additional cutbacks, both in 2020 and 2021. For not for profit organisations reliant in whole or in part on public fundraising, the true cost of COVID-19 will only be realised in the months ahead and into next year.

Over two thirds of disability services are provided by not for profit organisations, in terms of neurodisability services the percentage are much higher. Without significant support for Section 39 organisations, the entire model of community support for people with long term neurological conditions is under serious threat.

The NAI is supporting the Disability Action Coalition and other umbrella organisations in the disability sector in calling for:

- A special fund to meet COVID-19 fundraised income losses among not for profit service providers
- Reverse the 1% funding cuts applied to Section 39 organisations in January 2020
- Eliminate deficits for Section 39 disability providers and fund services at the actual cost of providing them
- Adopt all of the recommendations of the IRG report relating to Section 39 organisations
- Complete the process of pay restoration for workers in Section 39 organisations and ensure this is fully funded.

<sup>1</sup> Programme for Government: Our Shared Future (June 2020) Commitment to Continued Implementation of the National Neurorehabilitation Strategy Page 47

<sup>2</sup> Patterson et al (2020) The Emerging Spectrum of COVID-19 : Neurology, Clinical, Radiological and Laboratory Findings. Brain 8th July 2020 <https://academic.oup.com/brain/advance-article/doi/10.1093/brain/awaa240/5868408>

<sup>3</sup> NAI Submission to the Oireachtas Committee on COVID-19 (July 2020) [https://www.nai.ie/go/resources/nai\\_documents/nai-submission-to-the-oireachtas-committee-on-covid-19](https://www.nai.ie/go/resources/nai_documents/nai-submission-to-the-oireachtas-committee-on-covid-19)

<sup>4</sup> COVID19-The Impact on People with Neurological Conditions and Family Carers: Report of a Nationwide

Survey Carried Out by the Neurological Alliance of Ireland (May 2020) [https://www.nai.ie/go/resources/nai\\_documents/neurological-alliance-of-ireland-publishes-report-on-covid-19-nationwide-surveyhttps://www.nai.ie/go/resources/nai\\_documents/neurological-alliance-of-ireland-publishes-report-on-covid-19-nationwide-survey](https://www.nai.ie/go/resources/nai_documents/neurological-alliance-of-ireland-publishes-report-on-covid-19-nationwide-surveyhttps://www.nai.ie/go/resources/nai_documents/neurological-alliance-of-ireland-publishes-report-on-covid-19-nationwide-survey)

## ISSUES 2

### INCREASING DEMAND FOR NEUROREHABILITATION SERVICES WHICH WERE COMPLETELY UNDERDEVELOPED PRECOVID-19

**Pre COVID-19, the dearth of neurorehabilitation services undermined any potential for the development of successful trauma networks while also contributing significantly to the issue of delayed discharges in the health system.**

**Ongoing lack of investment in neurorehabilitation services now represents a serious threat to the capacity of the health system to manage the neurological consequences of COVID-19.**

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.

Lack of proper investment, means that hospital and community neurorehabilitation services in Ireland are completely inadequate with less than half of the inpatient beds required for a population of our size. Six out of nine Community Health Organisation

(CHO) areas have no community neurorehabilitation team in place, the remainder have only partially staffed teams. There is a huge dearth of appropriate residential, transitional, day and vocational neurorehabilitation services. A three-year implementation framework<sup>7</sup> for the National Neurorehabilitation Strategy published in February 2019 has seen no investment to date.

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.

<sup>5</sup> Impact of COVID-19 on people with disabilities and the disability sector: Submission to the Oireachtas Committee on COVID-19 (June 2020) Disability Federation of Ireland

<sup>6</sup> Submission to the Special Committee on COVID-19 response (May 2020) Disability Action Coalition <https://tdac.ie/publications/>

<sup>7</sup> National Policy and Strategy for the Provision of Neurorehabilitation Services In Ireland 2019-2021: From Theory to Practice (February 2019) Health Services Executive

## ASKS 2

**Investment of €4.5m in neurorehabilitation services as a first step in meeting the commitment in the Programme for Government to implement the National Neurorehabilitation Strategy.**

The Programme for Government commits to the implementation of the National Neurorehabilitation Strategy. A three-year implementation plan for the National Neurorehabilitation Strategy, published in February 2019, has seen NO investment to date. The Neurological Alliance of Ireland is calling for immediate additional funding to enable the implementation of the Neurorehabilitation Demonstrator Project in CHOs 6 & 7. This project is vital to:

- provide urgently needed neurorehabilitation services in counties Dublin, Kildare and Wicklow

- support the discharge of patients from the major neuroscience centres in Dublin which are experiencing lengthy hospital stays and delayed discharges due to the lack of neurorehabilitation services in the region
- reduce demand on the National Rehabilitation Hospital which has seen waiting lists and times steadily increase to unacceptable levels

The project was established in September 2018 with the appointment of a Project Manager but it has completely stalled due to lack of any funding to implement it.

## ISSUES 3

### INCREASING DEMAND ON NEUROLOGY SERVICES ALREADY COPING WITH THEIR HIGHEST EVER WAITING LISTS PRE COVID-19

Neurology services are provided in eleven main centres nationwide for the diagnosis and treatment of neurological conditions. NAI carried out a national audit in 2015 showing critical understaffing across all centres nationwide<sup>8</sup> but especially so in the regional centres in the North West (Sligo), Mid-West (Limerick) and South East (Waterford, Kilkenny) disenfranchises patients living in those regions. *Since the 2015 audit, OPD waiting lists have almost doubled<sup>9</sup> (from 13,460 in July 2015 to 22,458 in July 2020) but there has been little or no investment in neurology to keep pace with this demand.* This is despite a 20% year on year productivity increase in the number of patients seen in neurology clinics.

The Neurology Clinical Programme Consensus Statement<sup>10</sup> outlines that the COVID-19 pandemic has placed additional pressure on neurology services already experiencing among the highest outpatient waiting lists for any medical speciality pre COVID-19. Neurology services have faced significant changes in how outpatient clinics can be delivered, leading to potential further pressure on waiting

lists as large clinics with high numbers of people congregating in waiting areas are no longer possible. Neurology services have seen a significant backlog from the lockdown period which is placing further pressure on neurology staff, access to essential diagnostics and neuropsychology services. Ongoing management of COVID-19 will also place additional demand for neurology consultations for COVID-19 patients on top of a service already dealing with a significant backlog of neurology patients.

**Neurology services were already experiencing among the highest waiting lists for outpatient services within the health system. The backlog of appointments, the need to reduce the size of clinics, the ongoing need for strong preventative multidisciplinary care to minimise the need for hospital admissions and additional demand on already under resourced neurology and neuropsychology services cannot be met without additional resources.**

<sup>8</sup> Summary Findings First Audit of Neurology Services (2016) Neurological Alliance of Ireland [https://www.nai.ie/go/resources/nai\\_documents/15-2-2016-summary-findings-from-first-national-audit-of-neurology-services-in-ireland](https://www.nai.ie/go/resources/nai_documents/15-2-2016-summary-findings-from-first-national-audit-of-neurology-services-in-ireland)

<sup>9</sup> Outpatient Waiting Lists by Speciality <https://www.ntpf.ie/home/outpatient.htm>

<sup>10</sup> Consensus Statement on Neurological Care Post Covid19 Lockdown (June 2020) Clinical Advisory Group of the National Clinical Programme in Neurology

## ASKS 3

**Investment of €3.3m in Neurology Services to address critical understaffing in neurology services leading to the highest ever waiting lists now exacerbated by the COVID-19 pandemic.**

The Neurological Alliance of Ireland is supporting the National Clinical Programme for Neurology in calling for a €3.3m investment in acute neurology services in 2021 as follows:

- €1.3m via the Winter Planning initiative to provide 5 additional consultant posts to deal with critically high waiting lists and unsustainable (and unsafe) levels of consultant staffing in the regional centres of Waterford, Sligo, Limerick and the Midlands.
- €2m investment as follows:
  - €1.5m investment to extend the rollout of the Headache Pathway Project in 2021, a pioneering community-based model

which is critical to addressing the crisis in waiting lists (one quarter of OPD neurology outpatient lists are for headache referrals)

- €200,000 to begin to address critical shortages in Clinical Nurse Specialists for conditions such as multiple sclerosis, Huntington's disease, Parkinson's disease and muscular dystrophy.
- €300,000 towards multi-annual funding of a specialist motor neurone disease service, establishing a national centre of excellence for the management of rare neurological disease.

## SUPPORTING INVESTMENT IN SERVICES FOR SPECIFIC NEUROLOGICAL CONDITIONS

The Neurological Alliance is also supporting specific asks on behalf of its member organisations as follows:

### **€670,000 in Funding for Epilepsy Services to Deliver on Commitment to Services for Women with Epilepsy.**

NAI is supporting Epilepsy Ireland's call to ensure that all commitments made in 2018 to resource and implement the National Epilepsy Programme's 'Women's Health in Epilepsy' project are fulfilled in their entirety. Resources required include a consultant post, six adult ANPs and one paediatric ANP, a data manager, administrative support and funding to develop the Epilepsy Patient Portal and the Epilepsy & Pregnancy Register, at a total cost of €1m per annum. The consultant post and five ANP posts remain outstanding (€670,000).

### **€600,000 increase in annual funding for the MS Care Centre.**

NAI is supporting MS Ireland's call to increase annual statutory investment in the MS care centre by €600,000. The Multiple Sclerosis (MS) Care Centre is a 12 bedded unit which provides

respite care for people with MS and other progressive neurological conditions. This additional funding would see the MS Care Centre open 350 days a year providing an additional 1,128 bed nights annually. Increased investment would provide more people with the opportunity to avail of respite care, support carers and maintain the sustainability of home care.

### **€4.8m for Stroke Services in 2021.**

NAI is supporting the Irish Heart Foundation call for investment in stroke services in 2021 as follows:

- €300,000 to support rollout of FAST stroke awareness campaign
- €150,000 supporting delivery of thrombectomy services
- €2,384,327 Fund Year 1 of National Stroke Plan (HSCP staffing levels)
- €1,989,219 Save 5124 hospital days and a net cost saving of €1,398,226 by enhancing Early Supported Discharge programmes

## 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.

## FURTHER INFORMATION

Further information in relation to any aspect of this submission is available from:

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## NEUROLOGICAL ALLIANCE OF IRELAND 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



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