



10th July 2020

Dear Mr McEnergy

I would appreciate your assistance in forwarding the attached submission for consideration to the members of the Oireachtas Committee on COVID-19.

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 already at breaking point pre-COVID-19.

Neurological care services are critical to the management of COVID-19. More information is emerging about the neurological consequences of COVID-19 with implications for COVID-related demand on neurological care services, including neurorehabilitation. The Neurological Alliance of Ireland (NAI), the national umbrella for neurological charities, is concerned that the COVID-19 pandemic has unveiled the major deficits in neurological care in Ireland at a time when these services are critically needed in the fight against COVID-19.

While we welcome the commitments to the Neurorehabilitation Strategy, stroke services and dementia services in the Programme for Government, it is vital that immediate action is taken in order to protect existing services and develop critically needed capacity in neurological care nationwide in response to the COVID-19 pandemic.

I am happy to provide further information or representation on any aspect of this submission at the request of the Committee and look forward to your response. Please feel free to contact me by e mail mrogers@nai.ie or phone 086 1216957

Yours Sincerely,

Magdalen Rogers

Executive Director

Neurological Alliance of Ireland



Neurological Alliance of Ireland

Submission to the Special Committee on COVID-19 Response

Leinster House

10th July 2020

Executive Summary

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.

“Evidence strongly suggests that patients surviving COVID-19 are at high risk for the subsequent development of neurological disease” (Journal of Alzheimer’s Research & Therapy June 2020)¹

“We are facing a secondary pandemic of neurological disease” (Robert Stevens, Associate Professor of Anaesthesiology and Critical Care Johns Hopkins Medicine, Baltimore²)

Neurological care services are critical to the management of COVID-19. More information is emerging about the neurological consequences of COVID-19³ with implications for COVID-related demand on neurological care services, including neurorehabilitation. The Neurological Alliance of Ireland (NAI), the national umbrella for neurological charities, is concerned that the COVID-19 pandemic has unveiled the major deficits in neurological care in Ireland at a time when these services are critically needed in the fight against COVID-19

The NAI is calling on the new government to take immediate action to protect existing services and develop critically needed capacity in neurological care nationwide.

The Impact of COVID-19 on Neurological Care Services

-Impact on Specialist Community-Based Services and Supports for People with Neurological Conditions

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

¹ Heneka et al (2020) “Individual and long term consequences of COVID-19 infections for the development of neurological disease. Alzheimer’s Research & Therapy : 12: Article 69 (June 2020)

² How COVID-19 can damage the brain <https://www.bbc.com/future/article/20200622-the-long-term-effects-of-covid-19-infection>

³ Neurological and Neuropsychiatric Consequences of COVID19 in 153 patients-a UK wide surveillance study. June 25 2020. The Lancet: [https://www.thelancet.com/journals/lanpsy/article/PIIS2215-0366\(20\)30287-X/fulltext](https://www.thelancet.com/journals/lanpsy/article/PIIS2215-0366(20)30287-X/fulltext)

***“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 2020⁴ 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 Ireland⁵ 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.

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.

-Impact on Neurology Services

Neurology services are provided in eleven main centres nationwide for the diagnosis and treatment of neurological conditions. While an audit carried out by NAI in all centres⁶ showed understaffing across all sites, the chronic underfunding of services in the North West (Sligo), Mid-West (Limerick)

⁴ 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-survey
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⁵ 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

⁶ 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

and South East (Waterford, Kilkenny) disenfranchises patients living in those regions. There has been almost no development of national centres for those with rare neurological conditions for which new treatments are in sight (such as Huntington's disease, motor neurone disease and neuromuscular diseases).

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 despite 20% year on year productivity increases in the number of patients seen in neurology clinics. Neurology services will face 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 will no longer be possible. Neurology services already anticipate a significant backlog from the lockdown period which will place 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.

-Impact on Neurorehabilitation Services

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 framework⁷ for the National Neurorehabilitation Strategy published in 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.

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

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.

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

The NAI is calling on the new government to take immediate action to protect existing services and develop critically needed capacity in neurological care nationwide

Immediate Steps

1. Provision of a Crisis Fund for Disability Service Providers and Secure Statutory Funding 2020/2021

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.

2. Investment in Neurology Services to minimise the impact of COVID-19 on the delivery of high-quality equitable care for neurology patients

The Neurology Clinical Programme has developed a detailed consensus statement⁸ for the re-opening of neurology services post COVID-19, calling for the immediate reinstatement of all neurology staff deployed during the COVID19 outbreak and the provision of additional resources to address the increased demand for neurology, neuropsychology and diagnostic services. The document outlines the minimal investment required within each centre to meet the requirements for safe, effective delivery of neurological care at a time of increased demand now and into the future. This should include the provision of additional nursing and other neuro-specialist staff to provide high quality tele-medicine services and, where appropriate, posts that combine hospital and community-based support including home visits that prevent the need to travel long distances.

⁸ Consensus Statement on Neurological Care Post Covid19 Lockdown (June 2020) Clinical Advisory Group of the National Clinical Programme in Neurology

3. Implementation of the Three-Year Framework for the National Neurorehabilitation Strategy

The three-year implementation plan for the Neurorehabilitation Strategy, published in February 2019, has seen NO investment to date. The Neurological Alliance of Ireland has written to the new Minister for Health, requesting an immediate progress report on the work of the National Steering Group, which has only convened on two occasions since the plan was published.

The letter calls for immediate additional funding to enable the implementation of the Neurorehabilitation Demonstrator Project in CHOs 6 & 7. This project is a critical step in the implementation framework, although initiated in September 2018, it has completely stalled due to lack of funding.

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.

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
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