



**NEUROLOGICAL
ALLIANCE OF IRELAND**
PRE BUDGET SUBMISSION
2019



An Roinn Forbartha
Tuaithe agus Pobail
Department of Rural and
Community Development



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PRE BUDGET SUBMISSION 2019

2017 represented a landmark year for healthcare policy in Ireland with the publication of the Slaintecare report. By providing a political consensus on a health reform plan for the next ten years, this framework has the potential to deliver on a vision for new health service in Ireland. It is vital that neurological conditions are a key priority in this vision, given that they represent, according to the World Health Organisation¹, the greatest public health challenge facing health systems in developed countries worldwide.

THE NAI IS CALLING FOR:

- **Investment of €3m in neurology services to tackle critical understaffing, especially in regional centres**
- **Investment of €4.5m in neurorehabilitation services to begin a programme of investment in neurorehabilitation and to send an important signal of the Government's commitment to its own implementation plan**
- **The NAI is supporting calls for investment in home care, disability services and dementia services in the upcoming budget**

This year has seen important progress in providing a strategic direction for our health service in addressing the need for rehabilitation for people with neurological conditions. The publication of the recommendations of the steering group for a national trauma system for Ireland² and the imminent publication of the long awaited implementation plan for the National Neurorehabilitation Strategy³ have the potential, if implemented, to address the huge unmet need for rehabilitation services to promote recovery and prevent disability for people with neurological conditions. However, these plans will only deliver improvements in the lives of the over 25,000 Irish people each year who need neurorehabilitation services if they are accompanied by dedicated funding to support implementation.

Urgent action is required to address the crisis in neurology services which has seen waiting lists reach their highest level to date in 2018 and waiting times impacting on serious conditions where early diagnosis and treatment is vital in terms of outcomes.

Underinvestment and underdevelopment of neurological care services continue to have a serious impact, not only on the capacity of these services, but on the health system as a whole. The continued failure to properly invest in neurology and neurorehabilitation services is driving up waiting times and waiting lists, increasing pressure on accident and emergency departments and exacerbating the problem of delayed discharges.

¹ Neurological Disorders: Public Health Challenges (2006) World Health Organisation

² A trauma system for Ireland. Report of the National Steering Group (2018) Department of Health

³ National Policy and Strategy for the Provision of Neurorehabilitation Services in Ireland (2011) Department of Health & Health Services Executive

NEUROLOGY SERVICES

In March 2018, the NAI launched a campaign supported by eleven national charities calling for action to address the crisis in neurology services. No other term can be used to capture the extent of the challenges in a service where:

- Outpatient waiting lists for a first time appointment to see a neurologist continue to grow
- Waiting times to see a neurologist can be up to two years and waiting times between appointments are increasing
- Regional neurology centres are completely understaffed and some parts of the country such as the Midlands continue to lack an adequately resourced neurology service altogether

WAITING LISTS

The most recent figures from the NTPF show that in April 2018 over 20,000 people were waiting for a first time appointment to see a neurologist, 6,750 people were waiting longer than 12 months.

In January 2010, there were 9,217 patients waiting for a neurology OPD appointment. This represents a doubling in numbers in less than a decade. The type of growth in demand for neurology services is not being matched with additional resources. Nine WTE neurologists have been appointed within the last ten years. This represents a 30% increase in staffing leading to a 100% increase in OPD activity but this is still insufficient to meet demand and OPD waiting lists continue to grow.

WAITING TIMES

An AV room presentation in Leinster House on June 13th 2018 highlighted the issue of increasing waiting times for neurology services. The Model of Care for Neurology Services in Ireland⁴ recommends that people with multiple sclerosis start active treatment within 6 weeks of initial presentation, the best case scenario at the moment is 3 months.

A nationwide comprehensive patient experience survey carried out by the Neurological Alliance of Ireland in 2017 of two hundred people on their most recent experience of neurology services, reported an increasing anxiety among patients and a perception that services are struggling to provide them with care. Over 30% of patients reported that they were concerned at the length of time until their next appointment

UNDERSTAFFING AND UNDERRESOURCING ACROSS NEUROLOGY SERVICES, ESPECIALLY IN REGIONAL CENTRES

The findings of the 2015 audit of neurology centres⁵ carried out by the Neurological Alliance of Ireland and the Neurology Clinical Programme continue to reflect the national picture as there has been little investment in the meantime to address the critical deficits highlighted in this review.

⁴ National Model of Care for Neurology Services in Ireland (2017) National Clinical & Integrated Care Programmes, RCPI & HSE <https://www.hse.ie/eng/about/who/cspd/ncps/neurology/moc/>

⁵ Report on the National Survey of Neurology Centres (2015) Neurological Alliance of Ireland in partnership with the National Clinical Programme in Neurology http://www.nai.ie/assets/22/E622B527-41E1-4471-9EFD4E484E1745B2_document/NAI_Report_on_National_Services_2015_C.pdf

THE “INVEST IN NEUROLOGY” CAMPAIGN IS CALLING FOR:

- Immediate investment to address critical deficits in neurology staffing, including neurologists, specialist nurses and health and social care professionals to recommended levels
- Targeted long term investment in neurology services to support implementation of the Neurology and Epilepsy Models of Care
- Dedicated resources to support the development of clinical pathways for headache, multiple sclerosis, Parkinson’s disease and rare and genetic neurological conditions

Ireland has less than half the recommended number of MS nurses for its population and less than a third of specialist nurses for Parkinson’s disease. We have only three headache nurses, the recommended number is 32. There are no specialist nurses in Ireland at all for Huntington’s disease, an extremely disabling progressive neurological condition

A NATIONAL AUDIT OF NEUROLOGY SERVICES (2015)

A national audit of eleven neurology centres revealed critical deficits in staffing across all neurology centres with the most significant gaps in regional services.

- 4 of 11 hospitals reported NO dedicated OT services for neurology patients
- 5 neurology centres reported no dedicated speech and language therapy services for neurology patients
- Sligo hospital reported no dedicated posts for core supporting therapies for neurology patients including speech and language therapy, occupational therapy and physiotherapy
- None of the eleven neurology centres in the country had a full multidisciplinary team, nearly half of the centres lacked dedicated key therapies such as social work, speech and language therapy and occupational therapy
- Over half of neurology centres did not have any dedicated neurology beds, there are less than two thirds of the beds required to support our neurology services nationwide

These findings continue to reflect the situation in 2018

The **Invest in Neurology** campaign is calling for investment of €3m in neurology services in 2019 to support:

1. Appointment of consultant neurologists to address critical staffing deficits in regional centres such as Sligo, Waterford and Limerick where the minimum standard of three consultant neurologists to support a neurology service is still not in place and also in order to provide a neurology service to the Midlands.

Appointment of clinical nurse specialists to begin to address the significant shortfall in recommended numbers, especially in regional centres. There is strong evidence to support the value of clinical nurse specialists in the treatment of neurological conditions in Ireland. In 2017, the SENsE study funded by Epilepsy Ireland and the Health Research Board⁶ found that the involvement of CNS in the management of epilepsy led to:

- **Improved co-ordination and continuity of care, more prompt identification of problems and improved satisfaction with care**
- **A reduced attendance at emergency departments**
- **People with epilepsy in the study who received care from an ESN had the same costs as those treated in a non-ESN site but experienced better outcomes in the management and treatment of their epilepsy**
- **People with epilepsy had increased access to specialist epilepsy care and more services available to them**

The application of the clinical nurse specialist model to the management of other neurological conditions is key to improving outcomes for people with neurological conditions.

Development of the specialist motor neurone disease clinic in Beaumont Hospital as a demonstration site for the management of rare neurological conditions through specialist centres. This approach has already been demonstrated to be effective in reducing waiting times for specialist care and diagnosis, providing multidisciplinary care which has been shown to lead to improved outcomes for patients and by reducing costs of managing motor neurone disease through reduction in emergency admissions and pioneering of home treatment options⁷. Currently, the average time for a patient with motor neurone disease to attend a multidisciplinary clinic is 17 months, which is just under 50% of the total life expectancy, and locks patients out of many clinical trials.

⁶ An evaluation of the role of the Epilepsy Specialist Nurse and the Impact on Care: SENsE Study (2017) Epilepsy Ireland, TCD & Health Research Board http://www.epilepsy.ie/assets/61/0161AF49-7692-4A2F-97B3F3D5F5532CF6_document/SENsE_Report.pdf

⁷ <http://mnd.ie/research-blog/>

NEUROREHABILITATION SERVICES

In 2016 the Neurological Alliance of Ireland and fifteen of its member organisations launched a campaign “We Need Our Heads Examined”, calling for immediate action to address the dire shortage of rehabilitation services in Ireland. One of the key aims of this campaign continues to be the full implementation of the National Policy and Strategy for Neurorehabilitation Services. The “publication of a plan for advancing neuro-rehabilitation services in the community” represents a key commitment in the current Programme for Government. The Neurological Alliance of Ireland has been working with its member organisations, including specialist voluntary providers of neurorehabilitation services in the community to develop a three year implementation framework for the Neurorehabilitation Strategy. We understand this plan will be submitted to the Minister for Health in early July 2018 and it is therefore vital to ringfence new funding in 2019 to commence implementation. A critical aspect of this plan is the development of a nationwide network of community neurorehabilitation services. This approach is fully in line with the aims of Slaintecare to move towards a more community based model of healthcare provision which cares for people in their own communities, prevents disability and supports chronic disease management.

Investment in neurorehabilitation services is essential in order to develop an effective national trauma system for Ireland. The development of a national trauma system⁸ will require significant expansion of existing services and investment in new services in order to provide acute, post acute and long term rehabilitation for survivors of traumatic injuries. The report of the steering group, published earlier this year, highlighted that “the only post-acute specialist rehabilitation unit in Ireland is oversubscribed with long waiting times for access to specialist services (and) there

are also significant gaps in community level rehabilitation services”. Longer term, the National Planning Framework published in February 2018⁹, specifically references the redevelopment of the National Rehabilitation Hospital and establishment of Disability Rehabilitation Centres across the country.

While progress on publishing these initiatives in 2018 is welcome, they will fail to achieve any improvement in the lives of the 25,000 Irish people each year who need neurorehabilitation services, unless there is a clear commitment to dedicated funding year on year to address the huge existing dearth of neurorehabilitation services.

“Specialist rehabilitation is a critical component of the trauma care pathway without which, the trauma care pathway will fail”. Currently, Ireland has less than half of the specialist post acute rehabilitation beds (60 beds per million population) required

Not one additional community neurorehabilitation team has been established since the Neurorehabilitation Strategy was published in 2011. At least one team is required within each of the nine Community Health Organisation (CHO) areas. Currently, there are only three such teams in place in the entire country and they are only partially staffed

⁸ AA Trauma System for Ireland. Report of the National Steering Group (2018) Department of Health

⁹ National Planning Framework: Project Ireland 2040 (2018) Department of Housing, Planning and Local Government

The NAI is calling for investment of €4.5m in 2019 to support the development of post acute and community neurorehabilitation services in CHOs 6 and 7. This demonstration project represents an important initial step in the development of neurorehabilitation services nationwide but without dedicated investment it will be unable to achieve its key goals of improving access to services, reducing waiting lists and informing the development of further managed clinical networks for neurorehabilitation services across the country.

Most importantly, investment in the forthcoming Budget will be seen as an important signal of the Government's commitment to its own implementation plan and to addressing the overwhelming dearth of neurorehabilitation services in this country.

The demonstrator project in CHOs 6 and 7 aims to develop a managed clinical network for neurorehabilitation services in that area which will result in:

- **Development of community neurorehabilitation services, including dedicated community neurorehabilitation teams, to meet the long term needs of people with neurological conditions in the community to target significant unmet need for these services**
- **Addressing long waiting lists and delayed discharges in the national tertiary centre (NRH) by putting post acute and community neurorehabilitation services in place**

- **Providing a continuing platform to inform the rollout of neurorehabilitation services nationwide in accordance with the implementation framework for the Neurorehabilitation Strategy**

INVESTMENT IN HOME CARE, DISABILITY SERVICES AND DEMENTIA SERVICES

The NAI is supporting calls for investment in home care, disability and dementia services in the upcoming budget.

HOME CARE

Access to appropriate home care support, both in terms of suitability and sufficient resourcing continues to be a critical issue facing people with neurological conditions and their families¹⁰. While the Department of Health's plan to establish a statutory home care scheme by 2021 is welcome, investment is needed in successive budgets in the interim to resource home care support in view of growing waiting lists and increasingly limited provision. The NAI is supporting a range of patient representative organisations working in this area in calling for increased investment in home care in the upcoming budget.

Investment in home care also needs to address the need for intensive home care packages which are critical to enable people with neurological conditions to transition from hospital to home as well as for the long term care of people with progressive neurological conditions. Centralised, dedicated funding for intensive home care packages is required to meet increasing needs in this area.

¹⁰ NAI response to Public Consultation on a Statutory Scheme for Home Care (September 2017) http://www.nai.ie/go/resources/nai_documents/26-9-2017-nai-response-to-home-care-consultation

DISABILITY SERVICES & SUPPORTS

The NAI welcomes the pre budget submission launched by the Oireachtas group on Disability on 27th June, calling for a programme of investment in disability including:

- **A Multi – Annual Investment Programme in Health of €211m per year for 5 years across all disability services, including €55m for community services**
- **A €20 increase in Disability Allowance as an interim measure**
- **€1.5m investment in Assistive Technology**
- **€1.5 m investment in Education and Training Boards to support these agencies in the provision of education services to students with disabilities**
- **Other supports including 400 therapy staff to address waiting lists in children’s disability services and other supports including adult therapy, home care, residential supports and respite care**

Slaintecare makes a clear commitment to increased investment in home care and disability services which will need to be reflected in successive budgets to support the rollout of the ten year strategy for healthcare.

DEMENTIA SERVICES

There are almost 55,000 people in Ireland with dementia which affects people across a range of neurological conditions. The mid term review of the National Dementia Strategy¹¹, published earlier this year, clearly flagged the need for increased funding to support implementation.

The Neurological Alliance of Ireland is supporting its member organisation, the Alzheimer Society of Ireland, in calling for investment of €12m towards community supports for people with dementia in the forthcoming budget. (Note further content to be inserted subsequent to PBS launch 28.6.2018).

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. The work of NAI is supported through grant funding from the Scheme to Support National Organisations financed by the Department of Rural and Community Development (DRCD) and administered by Pobal.

FURTHER INFORMATION

Further information is available from Magdalen Rogers, Development Manager, Neurological Alliance of Ireland, Coleraine House, Coleraine St. Dublin 7, naireland@eircom.net or 01 8724120, 086 1216957.

¹¹ National Dementia Strategy: Mid Term Review (2018) Department of Health

MEMBERS OF THE NEUROLOGICAL ALLIANCE

Acquired Brain injury Ireland

Alzheimer Society of Ireland

An Saol

Aphasia Ireland

Ataxia Ireland

Bloomfield Health Services

Cheshire Ireland

Chronic Pain Ireland

Dystonia Ireland

Enable Ireland

Epilepsy Ireland

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Irish Heart Foundation

Irish Hospice Foundation

Irish Motor Neurone Disease Association

Migraine Association of Ireland

Move4Parkinsons

Multiple Sclerosis Society of Ireland

Muscular Dystrophy Ireland

Neurofibromatosis Association of Ireland

North West MS Therapy Centre

Parkinson's Association of Ireland

Polio Survivors Ireland

PSPA Ireland

Syringomyelia Support Group

Spinal Injuries Ireland

Spina Bifida Hydrocephalus Ireland

The Rehab Group

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