

MEMBER ORGANISATIONS OF THE
NEUROLOGICAL ALLIANCE OF IRELAND

Acquired Brain injury Ireland	Irish Heart Foundation
Alzheimer Society of Ireland	Irish Hospice Foundation
An Saol	Irish Motor Neurone Disease Association
Aphasia Ireland	Migraine Association of Ireland
Ataxia Foundation Ireland	Move4Parkinsons
Bloomfield Health Services	Multiple Sclerosis Society of Ireland
Brain Tumour Ireland	Muscular Dystrophy Ireland
Cheshire Ireland	Neurofibromatosis Association of Ireland
Chronic Pain Ireland	Neurology Support Centre
Crann Centre	North West MS Therapy Centre
Croí	Parkinson's Ireland
Dystonia Ireland	Peamount Healthcare
Dublin Neurological Institute	Polio Survivors Ireland
Early Onset Parkinson's Disease Association (EOPD)	PSPA Ireland
Enable Ireland	Slanu Stroke Rehab
Epilepsy Ireland	Spinal Injuries Ireland
FND Ireland	Spina Bifida Hydrocephalus Ireland
Headway	The Rehab Group
Huntington's Disease Association of Ireland	Vision Ireland



NEUROLOGICAL ALLIANCE
of IRELAND

GENERAL ELECTION
MANIFESTO
BRIEFING DOCUMENT

MAKE
BRAIN HEALTH
A PRIORITY

SEPTEMBER 2024

#INVESTINBRAINHEALTH

INVEST IN SERVICES, IMPLEMENT NATIONAL STRATEGIES AND PROTECT NEUROLOGICAL CHARITIES

WHY BRAIN HEALTH REQUIRES GOVERNMENT ACTION

Nearly one in six people in Ireland, 860,000, are living with a neurological condition with an estimated 50,000 people diagnosed with a neurological condition in this country each year¹.

With census 2022 showing a 22% increase in citizens over 65 years, the number of people at risk of neurological conditions associated with ageing is set to increase significantly.

Commitments in the next Programme for Government must reflect the scale of this challenge, enabling our health system to meet the growing numbers of people developing these conditions year on year and to meet Ireland's commitments to neurological conditions as a member of the World Health Organisation² and as a signatory to the UN Convention on the Rights of People with Disabilities (UNCPRD)³.

Investment in recent years has delivered real benefits for people with neurological conditions, their families and for our wider health services. However, significant gaps remain and vital services continue to be underfunded and overwhelmed by increasing demand.

GENERAL ELECTION MANIFESTO ASKS

The Neurological Alliance of Ireland is asking all parties and candidates to commit to making neurological care a political priority and pledge their support for the following actions.

ASK 1

IMPLEMENT EXISTING NATIONAL STRATEGIES FOR NEUROLOGICAL CONDITIONS

Deliver on Ireland's commitments under the WHO Intersectoral Global Action Plan for Epilepsy and Other Neurological Disorders (IGAP 2022-2031) to prioritise neurological disorders.

By – Committing to take the actions and provide the necessary investment to ensure timely diagnosis and specialist care for people with neurological conditions, in line with the national strategies for stroke and dementia, and the national models of care for neurology, epilepsy stroke and dementia.

ASK 2

DELIVER ON IRELAND'S COMMITMENT UNDER ARTICLE 26 OF THE UNCRPD TO PROVIDE COMPREHENSIVE REHABILITATION SERVICES

By – Committing to the full implementation of the National Neurorehabilitation Strategy and Model of Care for Specialist Rehabilitation within the lifetime of the next administration.

ASK 3

ENSURE THE CURRENT AND FUTURE SUSTAINABILITY OF THE NEUROLOGICAL CARE SERVICES PROVIDED BY VOLUNTARY SECTOR ORGANISATIONS

By – Responding to calls from across the voluntary sector to provide a sustainable funding model for Section 39 providers of health and disability services.

¹ Model of Care for Neurology Services in Ireland (2016)

² Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders 2022-2031 (May 2022) World Health Organisation

³ Article 26 (Habilitation and Rehabilitation Services) UN Convention on the Rights of People with Disabilities (2006) United Nations

MAKING THE CASE: Rationale and Background for Manifesto Asks

Ask 1

IMPLEMENT NATIONAL STRATEGIES FOR NEUROLOGICAL CONDITIONS

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By – Committing to take the actions and provide the necessary investment to ensure timely diagnosis and specialist care for people with neurological conditions, in line with the **national strategies for stroke and dementia, and the national models of care for neurology, epilepsy stroke and dementia.**

WHO INTERSECTORAL GLOBAL ACTION PLAN FOR EPILEPSY AND OTHER NEUROLOGICAL DISORDERS (2022-2031)

In May 2022, the 194 member countries of the World Health Organisation, including Ireland, signed up to a ten-year global framework, the Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders (IGAP 2022-2031) to improve access to treatment, care and quality of life for people with neurological conditions. Through outlining key objectives and targets, the IGAP provides an impetus for WHO member countries to tackle the growing challenge of neurological conditions for health systems worldwide. At the European Union level, the NAI fully supports the recommendations of the MEP Interest Group on Brain Health and Neurological Conditions which is calling for the establishment of a common implementation platform, to co-ordinate the implementation of the World Health Organisation IGAP across all member states. conditions.

NATIONAL MODELS OF CARE FOR NEUROLOGY & EPILEPSY

Targeted investment in neurology services has been shown to deliver tangible results in terms of better patient outcomes, reduced waiting lists and length of hospital stay. The rollout of a modernised care pathway for headache has led to significant improvements in waiting lists and length of stay through the introduction of specialist clinics, neurology specialist nurses and multidisciplinary teams. The development of a specialist centre for motor neurone disease has contributed to faster diagnosis and improved care and provides an important template for the management of rare neurological conditions.

However, much more needs to be done to address severe capacity issues in a medical specialty that has seen an exponential increase in demand and activity without the required year on year investment in staffing and facilities to create a neurology service that is fit for purpose. More than 22,000 people in Ireland are awaiting a first neurological appointment, and over 2000 of these are waiting more than 18 months⁴.

⁴ Outpatient Waiting List Data by Specialty Across all Hospitals (June 2024) National Treatment Purchase Fund Website www.ntpf.ie

⁵ Briefing Note on Specialist Nurse Staffing Levels in Ireland (December 2021) Neurological Alliance of Ireland



Ask 1

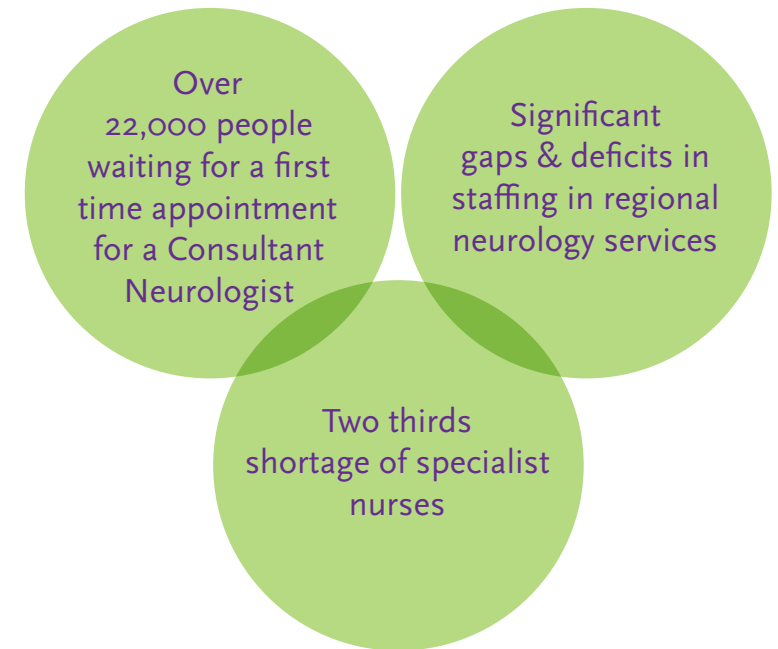
These waiting times are unacceptable given the critical need for early diagnosis and treatment for these serious brain conditions.

The Neurological Alliance of Ireland Patients Deserve Better Campaign, launched in November 2021, highlighted that Ireland has a shortage of one hundred nurse specialists across neurology services, based on a national survey of staffing levels in neurology services carried out in 2020 by the NAI in conjunction with the National Clinical Programme for Neurology⁵. Access to a nurse specialist is a crucial part of the care of a person with a neurological condition, yet as just one example the first national audit of movement disorders in Ireland found that only one fifth of patients with Parkinson's disease had seen a nurse specialist⁵.

The 2023 HSE service plan included funding for 21 specialist nursing posts in neurology, following an allocation in Budget 2022 by Minister for Disability Anne Rabbitte. In their testimony to the Oireachtas Committee on Health on 3rd July 2024, representatives from the HSE acknowledged that there had been significant administrative delays in providing hospitals with the go-ahead to recruit to these posts in 2023 and 2024. Even when these posts can be filled, Ireland will still have a two third shortfall in specialist neurology nurses.

Action is also required to address the significant gaps in regional neurology services to ensure that neurological patients are not at a disadvantage depending on where they live. Many of our regional hospitals have either no or very limited access to neurology services. The National Clinical Programme for neurology has highlighted concerns around this continued geographic inequity in access to neurology, which leads to

poorer access to care and poor outcomes in the regions outside the larger hospitals. It also leads to longer waiting lists in the larger hospitals to which all patients are referred, regardless of complexity. It is important to note that even in those regional hospitals which do have outpatient neurology services that this is provided by a single Consultant in many cases, with no access to a multidisciplinary team.



NATIONAL STRATEGY AND MODEL OF CARE FOR STROKE

Stroke is the second leading cause of death in middle to higher-income countries and the leading cause of acquired adult neurological disability in Ireland. Stroke is demonstrable



example in an Irish context of how investment can deliver on clear outcomes for neurological patients. Overall mortality from stroke has declined since 2008 from 19% to 11%. Access to thrombolysis has increased from 1% to 11%, thrombectomy from 0% to 8%. 764 patients were returned home with early supported discharge in 2022. This equates to approximately 10% of the total number of patients and approximately 25% of the patients served by an early supported discharge team. The National Stroke Strategy is aiming to have 21 Early Supported Discharge teams in place by end of 2025. The Irish National Audit of Stroke (2022) reported a median reduction in LOS of 8 days for those who went home with early supported discharge.

European projections for Ireland suggest an increased incidence of stroke up to 59% by 2035.

There is a critical need to realise the vision set out in the Stroke Action Plan for Europe through the full implementation of the National Stroke Strategy 2022-2027 and development and implementation of future strategic approaches to stroke.

Priorities for the National Stroke Strategy 2022-2027 include:

- 90% of all stroke patients to be admitted to a stroke unit
- Ensure adequate staffing resources to provide 24/7 acute stroke care and treatment and to support the stroke guideline recommendation for sufficient therapy post stroke
- Early Supported Discharge is an international model of best care for stroke patients. The National Stroke Strategy recommends 21 fully operational teams nationally, providing cover up to 95% of the population and seeing 20% of all stroke discharges

- Equitable access for all stroke patients to psychology services post stroke

NATIONAL STRATEGY AND MODEL OF CARE FOR DEMENTIA

Dementia is an umbrella term to describe a variety of diseases that affect the brain. Alzheimer's disease is the most common cause-responsible for approximately 60-70% of cases. Other causes include Lewy Body dementia, frontotemporal dementia, and many others. In Ireland it is estimated that over 64,000 people have dementia; this is predicted to double by 2045. The Model of Care (MoC) for Dementia, published in May 2023, builds on the principles of the National Dementia Strategy 2014, in emphasising the importance of timely diagnosis, interventions and supports for those with dementia and keeping the person affected at the core of the process.

National Dementia Services aim to realise all the targets of the Model of Care over the next 5 years, including an accessible memory service per 150,000 people and at least five regional specialist memory clinics (RSMCs) to meet the needs of those with more complex presentations, such as those under the age of 65, or those with more unusual cognitive difficulties.

If the Model of Care for Dementia is fully resourced and implemented approximately 10,600 people with cognitive concerns will be assessed, diagnosed and supported each year. Access to timely diagnosis will become ever more important as the first drugs that can slow the progress of Alzheimer's disease become available.

Ask 1

Increased investment in neurological care in order to implement the existing national strategies in neurology, epilepsy, stroke and dementia services. Comprehensive strategies have been developed which have, if implemented fully, the potential to transform care for people with neurological conditions in Ireland. What we need now is the investment to support their implementation.

Investment to Implement National Strategies in Neurology, Epilepsy, Stroke and Dementia

Tackle growing waiting lists and regional inequity through increased investment in neurology services

Address the two thirds shortage of specialist nurses across neurology services

Ensure adequate staffing to provide 24/7 access to acute stroke care and treatment and provide 21 Early Supported Discharge teams for Stroke nationwide

Continue investment in specialist dementia assessment and support services



Ask 2

DELIVER ON IRELAND'S COMMITMENT UNDER ARTICLE 26⁶ OF THE UNCRPD TO PROVIDE COMPREHENSIVE REHABILITATION SERVICES

By – Committing to the full implementation of the National Neurorehabilitation Strategy and Model of Care for Rehabilitation Medicine.

ACCESS TO NEUROREHABILITATION SERVICES IN IRELAND

Neurorehabilitation is the term used to describe the treatment that people can receive after they have had a neurological injury, illness or diagnosis of a neurological condition. The right to rehabilitation is enshrined in Article 26 of the UN Convention on the Rights of People with Disabilities (UNCRPD).

Ireland has among the most underdeveloped neurorehabilitation services throughout Europe. The 2019 Implementation Framework for the National Neurorehabilitation Strategy highlights that the landscape of neurorehabilitation services in Ireland is characterised by long waiting lists for specialist neurorehabilitation services, limited access to specialist rehabilitation for those who need it and a dearth of community-based specialist rehabilitation services and support services within the community to meet the long term needs of people with neurological conditions.

The Major Trauma Audit report (2021) highlighted that the proportion of major trauma patients who were discharged to inpatient

rehabilitation settings actually declined from 10% in 2020 to 7% in 2021. A survey of over 900 people with multiple sclerosis throughout Ireland carried out by the Multiple Sclerosis Society of Ireland and published in May 2024 found that only 2% had been able to avail of neurorehabilitation services. This is dramatically lower than a finding of 25% who had reported availing of neurorehabilitation services in 2016. The first national audit of movement disorders in Ireland, published in 2024, found that half of patients had no involvement of dedicated occupational therapy or speech and language services while 73% had no access to psychological support services. Most recently, the findings of the national Post Acute Inpatient Rehabilitation Mapping Project published in September 2024, found serious gaps in neurorehabilitation services with a 58% shortfall in specialist non tertiary neurorehabilitation beds in Ireland as well as lengthy waiting lists and staffing shortfalls within existing services. Further detail on these findings is provided later in this briefing document in the context of REGIONAL post-acute inpatient neurorehabilitation services.

6 States Parties shall take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life. To that end, States Parties shall organize, strengthen and extend comprehensive habitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services, in such a way

that these services and programmes:

- Begin at the earliest possible stage, and are based on the multidisciplinary assessment of individual needs and strengths
- Support participation and inclusion in the community and all aspects of society, are voluntary, and are available to persons with disabilities as close as possible to their own communities, including in rural areas

- States Parties shall promote the development of initial and continuing training for professionals and staff working in habilitation and rehabilitation services
- States Parties shall promote the availability, knowledge and use of assistive devices and technologies, designed for persons with disabilities, as they relate to habilitation and rehabilitation



Ask 2

THE IMPLEMENTATION OF THE NATIONAL NEUROREHABILITATION STRATEGY IS A KEY COMMITMENT OF BOTH THE CURRENT PROGRAMME FOR GOVERNMENT AND THE SLAINTECARE ACTION PLAN

A three year implementation framework for the National Neurorehabilitation Strategy (2019-2021)⁷ was published in 2019 which committed to:

- The establishment of **nine community neurorehabilitation teams**, one in each CHO (community health organisation) area to provide specialist rehabilitation up to a maximum of 12 weeks

- a range of **specialist community-based services** to meet ongoing and long-term neurorehabilitative needs beyond the timeframe and scope of that provided by the community neurorehabilitation teams
- provision of **inpatient rehabilitation services for acute, complex and post-acute rehabilitation** to meet the requirements of the Irish population. The Model of Care for Rehabilitation Medicine⁸ outlines a model for the delivery of Consultant Led specialist rehabilitation services through six managed clinical networks across Ireland.

Progress to Date (July 2024) in Implementing the 2019-2021 Framework National Neurorehabilitation Strategy: A key commitment under the 2020 Programme for Government and the Slaintecare Implementation Strategy & Action Plan 2021-2023

Community Neurorehabilitation Teams	Long Term Neurorehabilitation Services	Inpatient Neurorehabilitation Services
<ul style="list-style-type: none"> • Only 5 of the 9 CHO areas have teams funded to the minimum recommended staffing of 12 WTE • 2 CHO areas have no funding for teams to date (CHOs 5,8,) • 2 CHOs has a significantly underfunded teams (CHO 1 and 3) CHO 3 has a team of 5.6 instead of the minimum recommended 12 WTE. CHO 1 has only 3 WTE 	<ul style="list-style-type: none"> • Need for specialist community based services to meet ongoing and longer term neurorehabilitative needs 	<ul style="list-style-type: none"> • 58% shortfall in non tertiary post acute neurorehabilitation beds required for the Irish population • Lengthy waiting lists of 1-6 months for existing post acute inpatient neurorehabilitation services. Waiting times at National Rehabilitation Hospital (national tertiary centre) are 3-6 months

7 From Theory to Action: Implementation Framework for the National Policy & Strategy for the Provision of Neurorehabilitation Services in Ireland 2019-2021 (February 2019) Health Services Executive

8 Major Trauma Audit National Report (2021) National Office of Clinical Audit



COMMUNITY NEUROREHABILITATION TEAMS

Community neurorehabilitation teams are specialist multidisciplinary teams which form a crucial part of the neurorehabilitation framework, supporting people living with neurological conditions who require a period of intensive rehabilitation in the community.

Having community neurorehabilitation teams in place reduces length of stay and delayed discharges making better use of available beds in acute hospitals, prevents unnecessary admissions to acute hospitals and improves function and wellbeing for patients with a range of neurological conditions^{9,10}.

There has been welcome investment within the lifetime of the current Government to support the rollout of community neurorehabilitation teams, with full teams funded in five CHO (Community Health Organisation) areas. The Neurological Alliance has called for funding in Budget 2025 to complete the rollout of community neurorehabilitation teams and ensure all teams around the country are funded for 12WTE (whole time equivalent) in line with recommended staffing. Going forward, the NAI wants to see the expansion of teams of 12 WTE (whole time equivalent) to 18 WTE by 2026 in line with the commitment in the Action Plan for Disability services 2024-2026¹¹.

LONG TERM COMMUNITY NEUROREHABILITATION SERVICES

The 3-year Implementation Framework for the Neurorehabilitation Strategy 2019-2021 outlines the need for “specialist community based services to meet ongoing and longer term neurorehabilitative needs” beyond the 12 week intensive rehabilitation provided by the community neurorehabilitation teams. Much of the rehabilitative support needed in order to keep people well in their communities and achieve long term goals such as employment retention or retraining and community participation and integration, require longer term neurorehabilitative input beyond the twelve weeks intensive rehabilitation provided by the community neurorehabilitation team.

The Implementation Framework outlines long term neurorehabilitation services in the community as encompassing the following:

- Residential rehabilitation
- Transitional rehabilitation
- Community/home rehabilitation (to include intensive home care packages with a rehabilitative focus)
- Day rehabilitation
- Vocational rehabilitation
- Family Supports

These services already exist but there is widespread variation in access to these services across the country.

9 My MS, My Needs (May 2023) Multiple Sclerosis Society of Ireland

10 Azizi, Z., O' Shea, E., & Timmons, S. on behalf of the Mapping Parkinson's Steering Group. (2024). An Audit of Movement Disorder Services in the Republic of Ireland. Centre for Gerontology and Rehabilitation Services. University College Cork

11 Action Plan for Disability Services 2024-2026 (December 2023) Department of Children, Equality, Disability, Integration and Youth



Key to achieving this deliverable of the Strategy requires ensuring a sustainable and expanded provision of services by the voluntary sector as the established and experienced providers of long-term neurorehabilitation services in communities throughout Ireland.

POST ACUTE INPATIENT NEUROREHABILITATION SERVICES

The development of post acute inpatient neurorehabilitation services is a key commitment of the 2019 Implementation Framework for the Neurorehabilitation Strategy.

The findings of the HSE report “Post Acute Inpatient Rehabilitation Mapping Project: A National Overview of HSE Funded Services”¹² published in September 2024, shows a serious dearth of post-acute neurorehabilitation services and lengthy waiting times for existing services.

58% shortfall in Regional Neurorehabilitation Beds

The National Neurorehabilitation Strategy recommends 6 regional specialist neuro-rehabilitation beds per 100,000 population. This recommendation is in addition to the beds available in the national tertiary centre, the National Rehabilitation Hospital in Dun Laoghaire. Based on the 2022

census figures, this equates to a recommended requirement of 306 regional specialist neurorehabilitation beds nationally. The report findings show that the ratio of 6 beds per 100,000 was achieved in only one CHO (Community Health Organisation) Area. Table 1.1 shows the nationwide distribution of post-acute neurorehabilitation beds (excluding the complex specialist beds in the National Tertiary Centre, NRH Dun Laoghaire).

The findings of the report show a stark regional disparity in the location of existing beds, (see Table 11) with the West and South East (CHO s 2 and 5) being at a particular disadvantage.

The findings show a shortfall of 175 post-acute (non tertiary) neurorehabilitation beds across the country. This means that Ireland has **a 58% shortfall in the minimum number of post-acute neurorehabilitation beds needed for its population.**

Lengthy Waiting Times to Access Neurorehabilitation

The report also highlighted significant waiting times for existing neurorehabilitation inpatient units with almost half (47%) reporting waiting times of between one and six months.

For the National Tertiary Centre, the National Rehabilitation Hospital in Dun Laoghaire, 100% of patients were waiting from 3 to 6 months.

¹² Post Acute Inpatient Rehabilitation Mapping Project: A National Overview of HSE Funded Services (September 2024) Health Services Executive



Table 1.1 National Availability of Specialist Neuro-rehabilitation Beds (excluding the national tertiary centre)

Source "Post Acute Inpatient Rehabilitation Mapping Project: A National Overview of HSE Funded Services"

CHO	Counties	Number of Beds	Average Beds per Unit	CHO population	CHO Average Beds per 100,000
CHO 1	Sligo, Leitrim, Donegal, Cavan, Monaghan	13	6.5	413,980	3.1
CHO 2	Galway, Roscommon, Mayo	0	-	483,677	-
CHO 3	Clare, Limerick, North Tipperary	6	6.0	408,310	1.5
CHO 4	Cork, Kerry	10	10.0	736,489	1.4
CHO 5	South Tipperary, Carlow, Kilkenny, Waterford, Wexford	0	-	548,442	-
CHO 6	Wicklow, Dun Laoghaire, Dublin South East	32	10.7	420,485	7.6
CHO 7	Kildare, West Wicklow, Dublin West, South & South West	40	13.3	757,216	5.3
CHO 8	Laois, Offaly, Longford, Westmeath, Louth, Meath	8	8.0	679,475	1.2
CHO 9	Dublin North, Dublin North Central, Dublin North West	22	7.3	675,462	3.3
Total		131	9.4	5,123,536	2.6

Ask 2

Commitment to the full implementation of the Neurorehabilitation Strategy within the lifetime of the next Government in order to meet Ireland's responsibility to deliver rehabilitation services under Article 26 of the UNCRPD (UN Convention on the Rights of People with Disabilities).



9
FULLY STAFFED
COMMUNITY
NEUROREHABILITATION
TEAMS NATIONWIDE

TACKLE
THE TWO THIRDS
SHORTFALL IN POST
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COUNTRY

INVEST
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NEEDS

Ask 3

ENSURE THE CURRENT AND FUTURE SUSTAINABILITY OF THE NEUROLOGICAL CARE SERVICES PROVIDED BY VOLUNTARY SECTOR ORGANISATIONS

By – Responding to calls from across the voluntary sector to provide a sustainable funding model for Section 39 providers of health and disability services.

RANGE OF SERVICES PROVIDED BY THE VOLUNTARY SECTOR TO PEOPLE WITH NEUROLOGICAL CONDITIONS AND THEIR FAMILIES

*Source: Joint Neuromapping Project Phase I Report 2023

Findings from Phase 1 of the Joint Neuromapping Project¹³ published in 2023 found that the 44 voluntary neurological organisations surveyed were providing nearly one hundred unique services across Ireland to people with neurological conditions and their families all across Ireland.

The successful implementation of national strategies in neurological care is critically dependent on the network of voluntary sector organisations that deliver key specialist services and supports to people with neurological conditions and their families throughout Ireland. This network of neurological organisations is at serious risk because of the sustainability crisis facing voluntary providers of health and disability services.

The 2019 Report of the Independent Review Group¹⁴ established to examine the role of

voluntary organisations in publicly funded health and social care services (better known as the Catherine Day report) found that voluntary disability organisations deliver approximately two thirds of all disability services.

PAY PARITY ISSUE FOR VOLUNTARY PROVIDERS OF NEUROLOGICAL CARE SERVICES

The widely publicised pay gap between staff in Section 39 organisations and those in the public sector is having a detrimental impact on staff recruitment and retention in order to deliver the services provided by voluntary neurological organisations. Charities suffered a sharp decline in public funding after the financial crisis in 2008, as part of cuts affecting pay and staffing for all public services. These cuts were reversed, but only for public sector employees through the 2017 Public Sector Pay and Pensions Act and the Public Service Agreement “Building Momentum” deal. Cuts to the sector are yet to be restored. In June 2023, the Wheel and TASC published a report calling for Immediate State funding to address the two tier system of pay for organisations delivering public services on

¹³ The Neuromapping Project: Mapping existing services provided by the voluntary sector for people with neurological disabilities/conditions in the community (April 2023) Neurological Alliance of Ireland, Disability Federation of Ireland, Health Services Executive

¹⁴ Report of the Independent Review Group Established to examine the role of voluntary organisations in publicly funded health and personal social services (February 2019) Government Publications



Ask 3

behalf of the State. The report examined staffing, demand for services and funding among hundreds of Section 39, 10 and 56 organisations that receive contracts from the State to deliver essential public services countrywide in diverse areas like health, disability, family support, children, care of older people, homelessness and addiction. It found that staff were not legally entitled to the same pay as public sector employees delivering often-identical services, meaning that in some cases pay increases of up to 15% are required to tackle “negative disparity” compared to staff doing the similar work in state agencies.

Following the publication of the report, and to avoid strike action by thousands of affected organisations, a pay increase of 8% was agreed with the Workplace Relations Commission. Since then, a further public sector pay deal of an additional 10.25% has been agreed, leaving the sector further behind. Disparities in pay and conditions are having a serious impact on the ability of voluntary organisations to recruit and retain key staff. This undermines not only the sustainability of these organisations but the delivery of public services as well.

In addition, voluntary organisations face a host of other challenges under a funding model within the health services that has failed to keep pace with the actual cost to deliver services. These include rising costs associated with rent, insurance, cost of compliance with service quality and governance requirements, staff training, fuel costs etc.¹⁵



**The
Neurological
Alliance fully supports
the sector-wide call of
umbrella organisations,
including the Wheel and
Disability Federation of Ireland,
for a series of supports to enable
full recovery and promote
sustainability within the
voluntary sector**

Ask 3

Protection of vital neurological care services provided by voluntary organisations by providing a sustainable funding model for Section 39 providers of health and disability services.





If you would like any further information on any aspect of this briefing, please contact:

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ABOUT THE NEUROLOGICAL ALLIANCE OF IRELAND

The Neurological Alliance of Ireland (NAI) brings together over thirty non-profit organisations to advocate for the rights of the over 860,000 people in Ireland living with a neurological condition. Founded in 2003, the NAI advocates for the development of quality services for people with neurological conditions. Our campaigns are rooted in the experience of our members and the people and families with whom they work. We provide a united and expert voice on neurological care through advocacy, policy development and raising awareness.



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