



Neurological Alliance of Ireland

Response to the Call for Submissions from the Oireachtas Committee on the Future of Healthcare

August 2016



**An Roinn Tithíochta, Pleanála,
Pobail agus Rialtais Áitiúil**
Department of Housing, Planning,
Community and Local Government



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government supporting communities

Executive Summary

1. Over 800,000 Irish people are living with neurological conditions and 40,000 people are diagnosed with a neurological condition each year. The impact on health resources and health service infrastructure of these conditions is considerable and will increase as our population ages
2. The principal barrier to effective integrated care for people with neurological conditions continues to be underinvestment and underdevelopment of specialist services leading to gaps at all stages of the care pathway. There has been a dearth of commitment and leadership in the health system to date to address the needs of people with neurological conditions with reports remaining unpublished and failure to implement policy.
3. Lack of neurological care services continues to have a significant impact on the wider health system with longer hospital stays, delayed discharges and requirements for earlier admission to residential care. **Effective integrated care for people with neurological conditions is key to any future healthcare strategy because of the growing numbers of people with these conditions and the impact across the health system.**
4. The Neurological Alliance of Ireland are calling for the Ten Year Strategy for Healthcare to make neurological conditions a key priority within the health service

A Ten Year Strategy for Neurological Care must:

- Aim to address the critical shortages in staffing and specialist services for people with neurological conditions both in the hospital and community
 - Assign responsibility to a designated lead at senior level in the HSE for the development of neurology and neuro-rehabilitation services.
 - Implement the framework for neurology and neuro-rehabilitation services outlined in the models of care for Neurology and Rehabilitation Medicine and the National Neuro-rehabilitation Strategy
5. Meeting the needs of people with neurological conditions requires wider changes in the health system including removing barriers to accessing healthcare supports based on medical card eligibility and funding of long term services and supports for people living with neurological conditions and other disabilities in the community. Investment in proper information systems for the health services is critical to achieving integrated care and effective management of chronic disease and disability across the health system.
 6. The submission outlines a series of principles which should form for the basis for any future funding model for the health services in order to address the needs of people with neurological conditions. These include (i) the funding model is centred around the needs of

service users, providing real choices to address the entire range of health and social care needs of people with neurological conditions (ii) recognises and supports the role of not for profit organisations in delivering specialist responses to the needs of people with neurological conditions and (iii) ensuring that appropriate funding is available to secure the critical investment in neurological care that is required now and into the future.

7. The Neurological Alliance of Ireland has a strong track record of working with the health services, including as part of programme teams for the National Clinical Programmes in Neurology and Rehabilitation Medicine and is willing to work as a close partner with the health services going forward in identifying appropriate responses to meet the needs of people with neurological conditions.

Priority for a Ten Year Plan for the Health Service: Investing and Developing Services for People with Neurological conditions in Ireland

Services for the diagnosis, rehabilitation and treatment and long term support for the 800,000¹ people in Ireland living with neurological conditions are unfit to meet current need and completely inadequate to address future demands. An ageing population with increased prevalence of neurodegenerative conditions, the complexity of care presented by those living with paediatric neurological conditions into adulthood and those surviving traumatic and vascular acquired brain injury and the increasing availability of treatments for many neurological conditions is placing increasing demands on health systems throughout the developed world. The World Health Organisation has recognised this, highlighting that neurological conditions represent “the greatest public health challenge facing public healthcare systems in developed countries worldwide”. Ireland is no exception. Where we are exceptional is the extent to which, uniquely in the developed world, we have omitted to invest sufficiently in the development of neurological care to date, with the result that our health system continues to fail to address the needs of people with neurological conditions.

The second critical problem is an absence to date of a co-ordinated strategic approach to neurological conditions within the health services. The needs of people with neurological conditions have been examined through a series of reports and policy frameworks, some of which remained unpublished and others which have failed to be implemented to date. Responsibility for developing neurological care services lies across a number of divisions within the HSE, with no central strategic approach. Responsibility must be assigned at senior level the HSE to co-ordinate the development of neurology and neuro-rehabilitation services.

Neurological conditions have a significant impact on the wider health system. 17% of all GP appointments are for people living with neurological conditions and they account for one in ten visits to an accident and emergency department². The current situation where these services are either completely absent or underresourced to the extent that they cannot meet the level of need is resulting poor health and quality of life outcomes for people with neurological conditions. It also results in costly impacts across the health system, including delays³ and blockages⁴ within the hospital system and overcrowding in accident and emergency units because services in the community are either completely unavailable or inadequate to meet demand.

¹ Strategic Review of Neurology and Neurophysiology Services in Ireland (2007) Unpublished Report commissioned for the National Hospitals Office HSE

² Transforming Community Neurology: What Commissioners Need to Know (2016) NHS

³ The number of people waiting more than six months for a first time outpatient appointment to see a neurologist stands at 6,688 in June 2016 up by more than 1000 from January 2016 (Outpatient Waiting Lists by Speciality <http://www.ntpf.ie/home/outpatient.htm>)

⁴ In July 2016, 42 delayed discharges were directly attributable to waiting lists for rehabilitation services in the NRH and other hospitals

Effective integrated care for people with neurological conditions is key to any future healthcare strategy because of the growing numbers of people with these conditions and the impact across the health system. The Neurological Alliance of Ireland is calling on the Committee for the Future of Healthcare to identify neurological conditions as a key priority within a ten year plan for the health services.

Effective integrated care for people with neurological conditions within our health system can only be achieved through:

- **Investment in and development of specialist services** so that there is a viable care pathway for those with neurological conditions with appropriate services available to meet their needs at all stages of their condition
- **Implementing wider changes in the health system including removing barriers to accessing healthcare supports based on medical card eligibility and proper funding of long term services and supports for people living with neurological conditions and other disabilities in the community**

Underdevelopment and understaffing of specialist services for People with Neurological Conditions: Evidence of Need

Effective integrated care for people with neurological conditions requires appropriate services to be in place at each stage of the care pathway. Integrated care is inextricably linked to the issue of investment in and development of specialist services that can provide appropriate responses to the unique and complex needs of people with neurological conditions but also provide the critical expertise to support other areas of the health system in the appropriate management of these conditions. Evidence of need in terms of understaffing and underdevelopment of specialist services for people with neurological conditions is presented in detail in Appendix 1 of this submission.

Changes required in the wider in the Health System to Meet the Needs of People with Neurological Conditions

Effective and integrated care for people with neurological conditions continues to be impacted by the way in which our health system is structured and funded, which creates barriers to accessing healthcare services and supports and a lack of services to meet the needs of people with chronic illness and disability living in the community.

A Ten Year Strategy for Healthcare must address the following systemic issues within the health services which continue to impact on effective and integrated care for people with neurological conditions, and which significantly constrain the introduction of new models of service delivery based on improving integrated care:

1. **Reform of the Medical Card System and Long Term Illness Scheme**

Entitlements aimed at supporting access to healthcare actually create barriers for many people with neurological conditions

- (i) Access to a range of healthcare services in the community is dependent on having a medical card
- (ii) The financial burden associated with living with a chronic illness or disability needs to be properly assessed and reflected within the medical card system. The current system does not appropriately reflect the cost of living with a chronic illness/disability
- (iii) The Long Term Illness Scheme excludes many disabling neurological conditions

The NAI is calling for a ten year strategy for healthcare to implement the recommendations of the Expert Group⁵ on medical card eligibility and to review Long term Illness scheme, protecting existing and future recipients for the conditions currently under the scheme but widening entitlement to this scheme across the range of disabling neurological conditions.

2. Commitment to the development and resourcing of services in the community in line with Healthcare Policy

A shift in healthcare policy over the past two decades towards meeting the majority of healthcare needs in the community has failed to provide the resources and expertise required in the community to make this a reality⁶.

The lack of specialist services and staffing in the community to meet the needs of people with neurological conditions continues to result in unmet need and pressures on acute hospital neurology services and the only specialist rehabilitation centre in the NRH to deal with the consequences of lack of services for the long term management of neurological conditions. These include:

-pressures on secondary care to provide frequent review and readmissions to address needs which could be met in the community

-loss of treatment gains and deteriorations in functioning which make the management of neurological conditions more expensive in the longer term because of the need for hospital admissions and early transfer to residential care

Rehabilitation services in the community such as early supported discharge teams for stroke represent a vital link between the hospital and community in supporting effective integrated care for people with neurological conditions, helping to reduce the length of hospital stay, readmissions to hospital and admissions to long term care⁷

3. Provide a model of individualised supports for people with disabilities living in the community which is informed by and responsive to the needs of people with neurological disability

Reform of existing funding models within disability services to provide a system-wide resource allocation model based on individual support needs has the potential to provide greater equity and

⁵ Report of the Expert Panel on Medical Need for Medical Card Eligibility (2014) Health Services Executive

⁶ Report of the Expert Group on Funding and Resource Allocation within the Health Services (2009) Department of Health

⁷ Towards Earlier Discharge: Better Outcomes, Lower Cost. Stroke Rehabilitation In Ireland (2014) Report prepared for the Irish Heart Foundation by the Economic & Social Research Institute (ESRI) and Royal College of Surgeons (RCSI)

choice for people with disabilities⁸. The majority of people with neurological conditions do not live in traditional models of residential care, but wish to live in their own communities with the range of supports they require.

It is important that the introduction of a model of individualised supports for people with disabilities addresses the following needs of people with neurological conditions:

(i) the significant deficits in the availability of a range of specialist services for people with neurological disability currently present a barrier to individuals in accessing services to meet their needs. Investment in services for people with neurological conditions is critically required to provide people with a neurological disability with real options and choices about their care.

(ii) people with neurological disability must have access to qualified support to make informed choices about their service needs and accessing appropriate services to meet those needs

(iii) the assessment of individual need must appropriately capture the range of specialist supports and services required by people with neurological conditions and be flexible to reflect changes in their condition and circumstances over time

(iv) a model of funding support based on individual support needs must ensure that there is a co-ordinated approach to service provision for people with complex neurological disability through a central key worker or case management service.

5. Investment in Services to Support People with Neurological Conditions to live in their Communities, not in nursing homes and other inappropriate settings

People with neurological conditions are among those most impacted by the failure of the health system to invest appropriately in long term care options for people with chronic illness and disability that enable them to continue to live at home or in supported living settings that are appropriate to their needs. Currently, for the majority of people with neurological conditions, the lack of options for home support and appropriate residential care mean that they are accommodated in nursing homes which are completely inappropriate to their needs.

Real commitment to long term care options other than nursing home care must be a strategic focus for a ten year strategy for healthcare. The continued reliance on nursing home care is condemning people with neurological conditions to live in what amounts to a whole new iteration of the problem of congregated settings, denying them choices about where to live and access to a range of community healthcare services, including neuro-rehabilitation services, to meet their ongoing needs.

5. Investment in Information Systems to Support Effective Integrated Care for People with Chronic Conditions and Disability and a Strategic Vision for Research within the Health system

Provision of effective, integrated care for people with neurological conditions is significantly constrained by the lack of information systems both in the hospital and community.

⁸ The Introduction of Individual Budgets as a Resource Allocation System for Disability Services in Ireland (2011) National Disability Authority

The models of care in development for neurology and rehabilitation medicine services outline the vital importance of information systems based on a unique identifier to support effective integrated care for people with neurological conditions. Neurology services have been at the forefront of innovation in this area with the development of the electronic patient record for epilepsy, now being piloted across two other chronic health conditions, haemophilia and bi-polar disorder. Neurological conditions will require information systems that share information effectively across a range of health and social care settings if they are to be effective in meeting the long term needs of this population.

A ten year strategy for healthcare crucially needs to support a research infrastructure within the health services through funding, creating links between academic and hospital based research and ensuring that information systems are in put in place.

Key Principles for a Future Funding Model for the Irish Health Service to meet the Needs of People with Neurological Conditions

It is important to note that when the NAI uses the term “effective integrated care” we mean care that is not only responsive to the needs of people with neurological conditions but care that represents the best use of the healthcare spend to meet these needs in the immediate and long term and puts the user at the centre of healthcare provision, providing support and real choice in managing their healthcare needs.

A series of principles are outlined below which should underpin a future funding model for the health services that addresses the needs of people with neurological conditions as an increasing, and to date marginalised group of service users within the healthcare system.

1. The funding model must have as its fundamental focus the needs of users of healthcare services. This involves adopting an approach to funding health and social care provision for people with neurological conditions which provides for the following:
 - (i) Recognises that a wide range of factors contribute to positive health outcomes for people with neurological conditions and a future funding model for the health services must aim to support services which provide a holistic response to the range of social and psychological needs of people with these conditions.
 - (ii) Recognises that health outcomes for people with neurological conditions are inextricably linked to their requirements for practical supports in other areas of their lives including accessing to housing, transport, education, employment and training. A funding model for long term supports for people with neurological disability must provide appropriate support in accessing and co-ordinating the response of these services to needs of the person with a disability. Mobilising effective intersectoral commitment to meeting the needs of people with chronic illness and disability is a key commitment of existing frameworks^{9 10}but has been slow to deliver in practice.

⁹ Healthy Ireland: A framework for improved health and wellbeing 2013-2025 (2013) Department of Health

¹⁰ National Disability Strategy Implementation Plan 2013-2015 (2013) Department of Justice & Equality

- (iii) Recognises that people with neurological conditions need to be given real choices about where and how their healthcare is delivered, providing a funding model which supports people to continue to live in their communities with the support they need and that ongoing care and treatment can be provided as close as possible to where people live.
 - (iv) A funding model which supports people to be involved in their own healthcare through supporting self-management and service user involvement in the design and delivery of health services
2. The funding model should recognise the vital role of not for profit organisations in providing specialist services for people with neurological conditions and in supporting the response of the wider health services to meet their needs. Research by the Disability Federation of Ireland and Not for Profit Business Association highlights the significant added value to the disability sector¹¹ provided by voluntary disability organisations. The provision of specialist supports in the community for people with neurological conditions and their families is completely reliant on not for profit providers with many of these organisations underfunded and underresourced to cope with demand.

A future funding model for the Irish health services must provide a full and clear vision for the role of the not for profit sector, recognising that effective funding mechanisms and partnerships with the not for profit sector are critical to the provision of person centred responses to health and social care needs into the future.

3. The future funding model for the health services must be able to meet the needs of people with neurological conditions now and into the future by:
- (i) Addressing existing critical deficits in neurology, neuro-rehabilitation and long term care services for people with neurological conditions
 - (ii) Providing investment into the future to allow services to embrace new treatments and responses to the needs of people with neurological conditions. The future funding model must facilitate access to new medications for all those who would benefit from them
 - (iii) Supporting training and education of staff within specialist services but also across the health services in meeting the needs of people with neurological conditions

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.

¹¹ Living in the Community: Services & Supports for People with Disabilities (2013) Disability Federation of Ireland and Not for Profit Business Association

Further Information

The Neurological Alliance of Ireland has worked closely with its member organisations and with the Clinical Programmes in Neurology and Rehabilitation Medicine in the development of this submission. It is important to note however that this submission should not be taken to represent the collective views of all members of the Neurological Alliance and individual submissions will be made by many of our members to inform the work of the Committee.

The NAI has had the opportunity to input into the submissions from the Neurology and Rehabilitation Medicine Clinical Programmes and supports the recommendations outlined in those submissions.

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

List of NAI Member Organisations 2016

Acquired Brain injury Ireland
Alzheimer Society of Ireland
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
Neurofibromatosis Association of Ireland
North West MS Therapy Centre
Parkinson's Association of Ireland
Post Polio Support Group
Syringomyelia Support group of Ireland
Spinal Injuries Ireland
Spina Bifida Hydrocephalus Ireland
The Rehab Group

Associate Members

An Saol

Brain Tumour Ireland

Irish Association of Speech and Language Therapists

Irish Institute of Clinical Neurosciences

Irish Society of Physicians in Geriatric Medicine

Myasthenia Gravis Association of Ireland

PSPA Ireland

Appendix 1

Evidence of Need: Underinvestment and Underdevelopment of Services for People with Neurological Conditions

Neurology Services

In 2015, the Neurological Alliance of Ireland in collaboration with the National Clinical Programme in Neurology carried out a nationwide audit¹² of adult neurology services across the eleven neurology centres around the country. Key Findings include:

- The recommended ratio for consultant neurologist staffing is 1:70,000 population. This was exceeded in every hospital group. In the Mid West, the ratio was one consultant neurologist to 200,000 people
- Multidisciplinary teams were completely understaffed in many centres. 5 of 11 centres had no dedicated speech and language therapy, 4 had no dedicated occupational therapy

Neuro-rehabilitation Services

There are dire shortages in neuro-rehabilitation services across all levels of service provision.

- Inpatient specialist rehabilitation services are completely inadequate with less than half the number of recommended beds for our population and a lack of facilities outside Dublin.
- Neuro-rehabilitation services in the community are completely underdeveloped with only three partially staffed community neuro-rehabilitation teams across the country. One team per CHO (Community Health Organisation) is required as an absolute minimum.

Investment in neuro-rehabilitation services is critically required to address significant unmet need which is resulting in increasing disability and poor outcomes for people with neurological conditions and impacting on the wider health system with longer hospital stays, delayed discharges and earlier admission to nursing home care¹³. Plans to develop a trauma network for Ireland will require significant investment to address the dire shortages in rehabilitation services¹⁴.

Services for Children with Neurological Conditions

¹² Summary Findings from the First National Audit of Neurology Services in Ireland (2015) Neurological Alliance of Ireland http://www.nai.ie/go/resources/nai_documents/15-2-2016-summary-findings-from-first-national-audit-of-neurology-services-in-ireland

¹³ Model of Care for Specialist Rehabilitation Services in Ireland (Draft) <https://www.hse.ie/eng/about/Who/clinical/natclinprog/rehabilitationmedicineprogramme/docsforconsultation/modelofcare.pdf>

¹⁴ An Integrated Trauma System for Ireland (2014) Irish Association for Emergency Medicine

The National Model of Care for Paediatric Healthcare Services in Ireland ¹⁵ highlights the need for investment in services for children with neurological conditions to address deficits in neurosurgery services, access to inpatient rehabilitation and long term services in the community. Consultation with organisations working with children under the NAI umbrella points to the lack of specialist services at all stages of the pathway for children with neurological conditions.

Palliative Care

Research by the Neurological Alliance of Ireland and the Irish Hospice Foundation highlights the lack of specialist palliative care services for people with neurological conditions and the need for appropriate guidelines, support and training for staff working with people with neurological conditions in relation to meeting palliative care needs¹⁶ as well as the development of effective linkages and referral mechanisms from neurology and neuro-rehabilitation services to palliative care.

¹⁵ A National Model of Care for Paediatric Healthcare Services in Ireland: (2015)
<http://www.hse.ie/eng/about/Who/clinical/natclinprog/paediatricsandneonatology/modelsofcare/ExecutiveSummaryfinaldraft.pdf>

¹⁶ The Palliative Care Needs of People with Advancing Neurological Conditions (2014) Joint Study
Commissioned by the Neurological Alliance of Ireland and Irish Hospice Foundation