HIQA Health Technology Assessment of the Transition to and organisation of adult healthcare services for individuals with severe neurological impairment

Response to the Call for Submissions

November 2026

Executive Summary

The Neurological Alliance of Ireland, as the national umbrella of neurological patient organisations and as a member of the Expert Advisory Group for this HTA, broadly welcomes this report as a first step in recognising the challenges facing individuals with severe neurological impairment during the transition from paediatric services and beyond into adult care.

The complex needs of this group, to date underrecognised within existing policy frameworks, benefits from the methodological rigour and analysis of this HTA process, which delivers a comprehensive overview within its defined scope and provides a strong basis for further work. It is important however that a future model of service provision is not limited to the scope of this HTA and recognises that integration with health and disability supports within the community is integral to the health and wellbeing of individuals with SNI. Future work should also give consideration to examples of integrated care for complex neurological conditions in an Irish context, developed and delivered through collaboration between with clinical services and voluntary providers, provide important learning for a future SNI pathway that supports integrated care across transition and onwards into adult care.

The necessary action from this report should be to commission the development of an integrated pathway to meet the needs of people with severe neurological impairment to include both health and social care provision. An urgent consideration of capacity issues within neurological care services is also recommended, given the emphasis within the HTA that the need to strengthen capacity remains a foundational organisational priority for successful transition.

Overview of the NAI response

NAI welcomes the action of the Department of Health in commissioning this HTA to focus on the needs of individuals with severe neurological impairment and looks to this HTA as a first step in the development of a comprehensive response to the issues identified within this report.

As the national umbrella organisation for neurological patient organisations, and as a member of the Expert Advisory Group for this HTA, the NAI participation in this HTA brings a collective perspective across a wide range of neurological conditions.

NAI welcomes the specific focus on individuals with SNI as a population which to date has received limited focused attention in terms of healthcare policy and intervention despite the complexity and scale of their needs. The HTA provides a rationale and evidence base for the development of an integrated pathway for SNI and this should be actioned without delay following on from this report.

NAI acknowledges the expertise and support of its member organisations in informing this submission, together with advice from individual clinicians and other stakeholders. Above all, we welcomed the opportunity to reflect feedback from a small number of individual family members with lived experience of accessing care for a child with neurodisability which made an invaluable contribution to the insights and recommendations within this submission. We pay tribute to the HIQA team involved in this report for their openness to engagement and feedback throughout the process.

Strengths of the HTA

A strength of this HTA is its clarity and detail in outlining the structural disparity between coordinated, consultant-led and multidisciplinary paediatric neurodisability services and the fragmented adult healthcare system. Its central conclusion and admission that improving transition processes alone will not resolve these problems, reflects the experiences of voluntary providers and the individuals and families they work with.

A second important strength of the HTA is in its identification of the absence of an equivalent adult neurodisability service as a central systemic issue within the transition and ongoing care of individuals with severe neurological impairment. The report describes how young people move from coordinated paediatric care into a system in which responsibility is distributed across multiple adult specialities. This analysis is welcomed, it recognises that continuity cannot be achieved without an appropriate receiving service accompanied by sufficient resourcing.

The systematic review of healthcare service models for SNI is a particular strength of this HTA, providing a body of detailed information across other jurisdictions to inform potential future models of care. The conduct of this review in a time efficient and effective manner provides an important resource to provide the basis for the next steps of framework development, ensuring that a comprehensive review of international practice is already available to the action to develop an integrated pathway which immediately should follow on from this report. The HIQA team made every effort to work within the methodological constraints to extrapolate recurring features associated with improved continuity and care experiences. These include early transition planning, joint paediatric-adult clinics, multidisciplinary input, key-worker coordination with expertise in the area of care, information and a named clinician with overall responsibility.

The HTA is also strong in detailing the organisational requirements for a co-ordinated healthcare response. It outlines in comprehensive depth the core functions of named clinical responsibility, multidisciplinary input, a dedicated coordinator, shared care plans, clear referral pathways and governance and highlight the challenges of delivering these within the context of lack of current adult neurodisability pathways, services and specialist training, The chapter also engages in a detailed examination of the potential value of networked or hub-and-spoke arrangements in an Irish context, the need for interoperable information systems and clear governance. Again, the depth of this analysis and consideration provides a very useful critical analysis to guide future planning with the assurance that the insights have been obtained through a systematic evidence based programme of work. The observations of the report on the absence of national surveillance data or a dedicated patient registry for people with SNI are welcome and reflect a systemic issue in Ireland of the lack of patient registries and accurate prevalence data across neurological conditions. The point made in the HTA is essential in highlighting that this should not prevent action to develop services and interventions.

Limitations and Considerations

The most significant limitation is the absence of a budget impact analysis and an implementable programme of care with defined resource requirements. While NAI recognises HIQA's explanation that a budget impact analysis was not considered feasible once the evidence failed to identify a single optimal pathway, this weakens the impact of the HTA. However, it should be clear that this should not be used as a reason to in any way minimise the clear conclusions of the HTA and the utility of this report as a sufficient foundation for immediate next steps for pathway development.

The HTA recognises as a limitation its exclusion of community and social care services. This exclusion overlooks a fundamental characteristic of severe neurological impairment as a long- term condition with ongoing needs for therapeutic and healthcare supports in the community that are essential for health and wellbeing. These services play an important role in maintaining function rather than addressing medical and other needs in a reactive manner. This interdependence of hospital and community based service provision is reflected within a number of the models of transition and of organisation of adult healthcare

described within the systematic review which include primary care and community as key components of service delivery.

In excluding community and social care services from its scope, the HTA also overlooks one of the most significant challenges of the transition process for complex neurological conditions which is the gap between discharge from hospital based paediatric services at sixteen years and the age threshold for access to adult disability supports at eighteen years. This is experienced across a range of neurological conditions where the multidisciplinary care provided by the paediatric team that co-ordinates needs around rehabilitation, equipment, personal assistance and other complex care needs is replaced by individual care services within the adult system with dual problems of age thresholds to access these services and a lack of co-ordinated response due to capacity or other issues that impact the timing and level of intervention. Both can result in a significant gap in care at the critical point of transition from paediatric to adult services.

It is vital that this limited scope in the context of the methodological constraints of a health technology assessment does not carry forward as a precedent for a service model for the management of severe neurological impairment in an Irish context. Such an approach would be artificially limited to exclude a consideration of needs which are integral to the health and wellbeing of individuals with SNI and locates the focus of their care within a hospital setting which should be reserved for the most complex care. The next step must be to consider how the organisation of secondary care services outlined in the HTA integrate in a seamless way with effective community and disability service provision.

A weakness of the HTA is the absence to date of a structured mechanism for lived experience to inform the HTA and its findings. People with SNI and their families have direct knowledge of the difficulties encountered at transition, including gaps in clinical responsibility, delays, fragmented care and the challenges of accessing supports. The representation through the Neurological Alliance of Ireland of voluntary providers at the frontline of supporting individuals and families with severe neurological impairment, should not been seen as a substitute for direct lived experience representation in line with HIQA's own guidance for the active involvement of service users at all stages of policy development.

Lived experience insights collected by NAI in the development of this submission clearly identified a number of considerations that risk being underemphasised in the current report narrative. These include the barrier presented by the physical accessibility of healthcare settings with lack of functioning hoists, toilet and changing facilities and physical space experienced as real barrier to accessing healthcare. In addition, a gap in the narrative is the extent to which care breakdown is a feature of lived experience. The report highlights the lack of effective co-ordination between services as a significant challenge for families with the responsibility of co-ordinating multiple appointments, sharing information and repeating medical information in multiple contexts. The feedback received by NAI highlights that it is not alone care co-ordination but care breakdown that is the most significant cause of stress, anxiety and poorer outcomes. This can occur due to multiple reasons , due to staff leave or staffing gaps, when the family moved to a different part of the country or when a

new need arises. Case management/key worker roles are essential to enable families to navigate these challenges.

Lived experience feedback to NAI outlined that the transition pathway for individuals with severe neurological impairment should be a structured, person-centred and adequately resourced process that prioritises continuity of care, individual needs and the rights of the young person. Transition must involve comprehensive, individualised assessments and formal handover of all relevant services, including neurology, neurorehabilitation, therapies, disability supports, home care, respite and palliative care where appropriate. Each receiving service should confirm its readiness and formally accept responsibility before paediatric care ends. A coherent lifelong health record, accessible emergency plan and clear arrangements for equipment, assistive technology and ongoing maintenance are essential to prevent gaps in care. Eligibility should be based on clinical complexity, functional needs and multidisciplinary dependency rather than diagnosis alone, including young people without a definitive diagnosis. The pathway should also address decision-making support, financial entitlements and access to independent advice, while protecting the young person's autonomy. Families and young people must have accessible information, opportunities to raise concerns and a clear escalation and independent review process where transitions are incomplete or unsafe. The HTA recognises that there is a lack of consensus on what constitutes a successful transition Feedback from service users and service providers, including voluntary providers are key in this regard. Transition should be considered complete only when all necessary adult services have accepted responsibility and safe, coordinated care is functioning.

Feedback also highlighted the importance of consideration of palliative care where appropriate in a future pathway for individuals with severe neurological impairment. The HTA acknowledges that individuals with SNI may require palliative care during the course of their disease and/or at end of life, and that this may be delivered at home or as an inpatient. It is important to highlight that palliative care can be beneficial from the point of diagnosis of a life-limiting condition and throughout the person's life, sometimes over many years. It can be provided alongside active treatment and ongoing management, with the aim of improving or maintaining quality of life, managing symptoms and supporting both the individual and their family. All healthcare professionals should be supported to incorporate a palliative care approach into their everyday practice, whether working in primary care, the community, residential settings or acute hospitals. Specialist palliative care teams should be accessible when more complex needs arise, but the principles of palliative care should be embedded across all services and settings.Early and ongoing advance care planning conversations can help young adults and their families explore what matters most to them, understand treatment options, communicate preferences and plan for potential deterioration or emergency situations. This should be a supportive, person-centred and evolving process, rather than something introduced only when someone is approaching end of life. It is particularly important that these plans are documented and communicated across paediatric and adult services, so families are not repeatedly having to navigate difficult decisions without continuity or clear information.

Methodological considerations of the limited response rate to the paediatric hospital survey and incomplete information on service availability and regional distribution represent weaknesses in the information available to inform the findings of the HTA. Nevertheless the conclusion from the HTA is welcomed in outlining that the absence of a definitive population estimate should not delay the development of services. The evidence already demonstrates a significant gap in provision and an identifiable cohort approaching or requiring adult care.

While not a weakness of the report, the definition of severe neurological impairment did present challenges for NAI stakeholders in understanding and engaging with the HTA and the consultation process. Both service providers and families were not familiar with the term, which was only introduced in 2020, and felt that application of strict diagnostic criteria for SNI risks excluding individuals with significant impairment who do not meet the full definition for SNI.

The HTA focused on identifying models of transition and adult healthcare specifically developed for the SNI population. Engagement with both statutory and voluntary providers in the development of this submission highlighted to NAI that there are important learnings from service models that have been developed in an Irish context to address transition and long term needs in complex neurological conditions. While these focus on a wider range of neurological conditions and represent a transition where there is a clear pathway to a consultant-led adult service, they have been developed to address many of the same challenges associated with transition that are identified in the HTA including provision of a single point of co-ordination, communication between service providers and effective supports for individuals and their families in navigating complex care systems.

Central to many of these models of transition support is the recognition that effective bridging between hospital and community is as important to transition as the linkage from paediatric to adult hospital based care. Voluntary providers have developed a body of expertise in designing and delivering integrated care for complex neurological conditions that is aimed at providing specialist support from the earliest stages, acting as a consistent single point of contact in navigating multiple services and transition points and providing responses across the wide range of health and social care needs for these individuals and their families. Key worker, family liaison and case management models within the voluntary sector are integral to successful transition and long term care for people with a neurological disability.

The Neurological Alliance of Ireland has an established network of stakeholders in order to bring the learnings and insights from existing service models and approaches to complex neurological conditions to the next step of developing an integrated service response to the needs of individuals with severe neurological impairment.

Addressing Service Capacity and Availability As a Central Message of this HTA

The HTA repeatedly highlights that the transition process is contingent on the capacity and availability of services before, during and beyond the transition process. The HTA repeatedly refers to gaps in resourcing and staffing deficits across paediatric and adult services for children and young people with neurological conditions. Individuals with SNI, together with the wider population of children and young people with complex neurological conditions, are dependent on a neurological care system where significant gaps in the capacity and availability of services is having an ongoing impact on the level of care they receive not just in the lead up to and during transition but beyond into adulthood.

A key consideration must be to address the impact of capacity issues in neurological care, recognised in this HTA as core requisite for successful transition and long-term outcomes for individuals with severe neurological impairment. A concern repeatedly voiced by lived experience, voluntary service providers and clinicians to NAI in the course of developing this submission was that timely access to consultant-led review across neurology and neurodisability services continues to be significantly impacted with increasing periods between appointments coming at a critical juncture at the very point of transfer to adult services. This is leading to a pattern of delayed transition, a breakdown in care and significant anxiety and concern for individuals and their families. This issue is not confined to those with severe neurological conditions and significantly impact transition outcomes across the range of neurological conditions even when an adult pathway is in place. It is approaching a decade since the publication of the Model of Care for Paediatric Healthcare[1] and the Model of Care for Neurology[2] with many of the recommendations to address service capacity still remaining to be implemented. An urgent consideration of capacity needs within neurological care services is critical to future service provision to meet the needs of individuals with severe neurological impairment at all stages of care, including the transition to adult services.

This section of the NAI submission provides an overview of the gaps across neurological care services, outlining where the recommendations of existing healthcare policy have not been sufficiently implemented to address the growing volume and complexity of need.

Paediatric Neurology, Specialist Rehabilitation and Neurodisability Services

Paediatric service resourcing receives limited attention in the HTA, with the emphasis primarily on the capacity and availability of adult neurodisability services for the SNI population. Appropriate resourcing of paediatric neurology, neurodisability, specialist rehabilitation and disability services is key to providing integrated care for individuals with

[1] National Clinical Programme for Neurology Model of Care (2016) Royal College of Physicians of Ireland (RCPI) & National Clinical & Integrated Care Programmes Health Services Executive
[2] Health Service Executive (HSE) and Royal College of Physicians of Ireland (RCPI), National Clinical Programme for Paediatrics and Neonatology (2015). A National Model of Care for Paediatric Healthcare Services in Ireland. Royal College of Physicians of Ireland (RCPI) & National Clinical & Integrated Care Programmes Health Services Executive

SNI and other neurological conditions across childhood and in the lead up to the transition to adult services.

The demand for paediatric neurology services in Ireland has shown an exponential increase due to significant advances in medical care that have improved survival rates among children with complex neurological conditions. It is estimated that 33% of paediatric emergencies are neurological and 20-25% of paediatric admissions require paediatric neurology consultation.

Advances in neonatal intensive care, neurosurgery, and chronic disease management mean that more children with the complex neurological conditions encompassed under the SNO definition are surviving into childhood and adolescence. At the same time, rapid progress in genetic testing and precision medicine has led to earlier and more accurate diagnoses, enabling targeted treatments for previously untreatable disorders. These developments, while greatly enhancing quality of life and long-term outcomes, have also created a growing need for ongoing specialist neurological care, multidisciplinary support, and long-term management. As a result, paediatric neurology services in Ireland are experiencing sustained growth in demand, with current staffing levels falling far short of what is required. As a consequence, children and their families are experiencing longer waiting times for initial appointments, lengthy times between follow up appointments which has a significant impact on their care and critical gaps in the multidisciplinary care that needs to be place in order to meet the needs of children with these complex and life changing conditions. The pressure to see children on waiting lists means a longer time between follow up appointments , meaning that children are missing developmental milestones and falling behind before they can be seen again by services. An increasing gap between appointments, directly attributable to capacity issues, has significant implications for children and young people at all stages of the care but particularly at the transition stage, when children may miss a vital window of intervention and support in the move to adult services

The Model of Care for Paediatric Healthcare in Ireland outlines a series of recommendations for the configuration and staffing required for paediatric neurology.The ratio of paediatric neurologists in developed countries ranges from 1/100,000 to 3/100,000 in children aged under 16 years. There is a general consensus that the upper end of this ratio, i.e. 3 per 100,000 is required given the increased complexity and clinical input required to deliver the emerging treatments and diagnostic procedures now available to treat these conditions. At this ration, Ireland falls far short of the level of paediatric neurology staffing required, especially in regional areas. There is also a serious dearth of specialist nursing and multidisciplinary care across paediatric neurology services with specialist nursing playing a critical role in care co-ordination and management of neurological conditions.

Developments and advances in a number of areas offer significant hope to individuals with SNI and their families but place a critical reliance on paediatric neurology to administer and monitor treatments. The many examples include drug treatments for spinal muscular atrophy, gene therapy and enzyme replacement for Battens disease, preparing for and communicating to families around genetic testing and results, administering disease modifying therapies, addressing complications from cardiac procedures and supporting oncology treatment.

The HTA identifies rehabilitation medicine as one of the key specialties involved in the care of both children and adults with severe neurological impairment. Development and resourcing of paediatric specialist rehabilitation services in line with the tiered integrated rehabilitation service recommended in the Model of Care for Paediatric Healthcare has not progressed sufficiently since the report was published nearly a decade ago. The ongoing dearth of specialist rehabilitation across hospital and community continues to have a significant impact on outcomes for children and young people with severe neurological impairment and other conditions requiring specialist rehabilitation.

Only 1% of children with severe acquired brain injury are discharged directly from hospital to inpatient specialist rehabilitation, contrasting with 10% of adults. Many children are discharged from acute hospital to limited service provision at community level while they wait for access to limited national inpatient specialist services. At community level, children's network disability teams are not designed to provide ongoing neurorehabilitation and in most cases they lack the expertise and level of staffing required to provide intensive neurorehabilitation.

The HTA clearly references the dearth of consultants in neurodisability within the paediatric system. The Model of Care for Paediatric Healthcare recommends 40 paediatricians with a specialism in neurodisability, with the HTA reporting just 17 currently nearly a decade on from the publication of these recommendations. There is also a critical dearth of specialist nursing and multidisciplinary teams within paediatric neurodisability services.

Community Disability Network Teams (CDNTs) are intended to provide multidisciplinary support to children with complex disabilities including neurological conditions. Their core workforce includes physiotherapy, occupational therapy, speech and language therapy, psychology, social work and nursing, with access to other disciplines such as dietetics and family support. For children with neurological conditions, these services can be fundamental to maintaining function, preventing secondary complications and supporting communication, mobility, feeding, participation and independence. However, the national CDNT workforce remains below the level required to meet demand[3]. For children with SNI these workforce pressures may have a disproportionate impact. Neurological disability frequently requires co-intensive, sustained, co-ordinated input from several disciplines. It is acknowledged that CDNT's lack the specialist workforce, capacity and neurological expertise to address the needs of children with neurological disability, including SNI.

Adult Services

Adult neurology services are identified within the HTA as a principal specialty involved in the care of individuals with SNI. The HTA explicitly identifies capacity constraints within adult neurology services, stating that consultant posts in neurology are limited, structured multidisciplinary teams are not routinely available, and access to specialist nursing and therapy varies significantly across centres, with significant regional disparity across the

[3] National Children's Disability Network Team Workforce Report (2025) Health Services Executive

country. Outpatient neurology services have seen a quadrupling of referrals nationally over the past five years.

The Neurological Alliance of Ireland 2026 report, *Towards an Integrated Equitable Neurology Service for Ireland*[4], provides compelling evidence that adult neurology services are already operating within a context of significant workforce deficits, growing demand and marked regional variation in access to specialist and multidisciplinary expertise. These system-level constraints are highly relevant to the healthcare needs of people with severe neurological impairment (SNI). The NAI national resource survey across all ten designated neurology centres demonstrated substantial variation in staffing and access to multidisciplinary expertise. The scale of existing pressure is further demonstrated by the over 18,000 people on an outpatient waiting list for neurology services[5]. In common with paediatric neurology, adult neurology services are facing increasing demand due to the requirements to monitor and administer new treatments and the increased complexity of care.

The 2016 Model of Care for Neurology emphasises that transition from paediatric to adult neurology should be a planned phased process with preparation beginning in early adolescence. Capacity issues in adult neurology services continue to have a significant impact on transition across the population of children and young people with neurological conditions with individuals with SNI with the most significant and complex needs being among the most vulnerable to the impact of underresourced neurology services.

Recommendations

For this report to be meaningful/have the desired impact the NAI recommends that an immediate next step from this HTA should be to develop a seamless, person-centred pathway to meet the needs of people with severe neurological impairment.

While the HTA provides an important evidence base for identifying the challenges experienced by this population in accessing secondary healthcare, the pathway must extend beyond hospital-based healthcare provision to encompass the wider community healthcare, neurorehabilitation and disability supports that are essential to maintaining health, wellbeing and quality of life for people with severe neurological impairment. For people with complex neurological needs, continuity of care depends not only on access to specialist medical expertise, but also on timely access to co-ordinated disability services. This is the message that is being continuously reiterated to us family members/carers of those with SNI (lived experience) as well as individuals working in this area. The expertise developed by patient organisations in providing key worker, case management and family support

[4] Towards an Integrated Equitable Neurology Service for Ireland (April 2026) Neurological Alliance of Ireland

[5] Open Data Report Outpatient Waiting List by Speciality 2026. National Treatment Purchase Fund Website November 2026

functions should also inform consideration of how coordination can be maintained during transition from paediatric to adult services and onwards into adult care.

The HTA is consistent in highlighting service capacity and availability as a critical factor in transition from paediatric to adult services. An urgent consideration of capacity needs within neurological care services is critical in order to address the challenges in relation to the transition from paediatric services and onwards into adult care that are outlined in the HIQA report.

Further Information

For any queries or further information in relation to any aspect of this submission, please contact the Neurological Alliance of Ireland at mrogers@nai.ie

About the Neurological Alliance of Ireland

The Neurological Alliance of Ireland brings together nearly 40 non-profit organisations to advocate for the rights of the over 860,000 people throughout Ireland living with a neurological condition. Neurological conditions affect the brain and spinal cord and now represent the leading cause of disability worldwide. Founded in 2003, the NAI advocates for the development of quality services for people living with neurological conditions. Our campaigns are rooted in the experiences of our members and the individuals and families with whom they work. We provide a united and expert voice on neurological care through advocacy, policy development and awareness raising. More information can be found at www.nai.ie.

Member Organisations of the Neurological Alliance of Ireland

Acquired Brain injury Ireland
Alzheimer Society of Ireland
An Saol
Aphasia Ireland
Ataxia Foundation Ireland
Bloomfield Health Services
Brain Tumour Ireland
Cheshire Ireland
Chronic Pain Ireland
Crann Centre
Croí
Dystonia Ireland
Dublin Neurological Institute
Early Onset Parkinson's Disease Association (EOPD) Ireland

Enable Ireland
Epilepsy Ireland
FND 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
Neurology Support Centre
North West MS Therapy Centre
Parkinson's Ireland
Peamount Healthcare
Polio Survivors Ireland
PSPA Ireland
Spinal Injuries Ireland
Spina Bifida Hydrocephalus Ireland
The Rehab Group
Vision Ireland