

Response to the Call for Submissions

Public Consultation on Disability Act: September 2026

Executive Summary

Neurological conditions are now among the leading causes of disability worldwide according to the World Health Organisation. In Ireland, the most recent report of the National Ability Supports System highlighted that 22% of the adults engaging with disability services in 2025 had a neurological condition as the primary cause of their disability¹.

The main focus of this submission is on the actions required to ensure that the review of the Disability Act reflects the needs and experiences of the growing numbers of the Irish population with a neurological disability.

The submission draws on the 2026 report “The Disability Act at 21, Reflecting, Reforming Reimagining²” by the University of Galway, the 2026 report from the Oireachtas Committee on Disability Matters³ as well as the National Strategy for Disabled People 2025-2030⁴.

There is a substantial body of reports and commentary calling for substantial review of the Act, including to bring it into line with Ireland’s commitments under the United Nations Convention on the Rights of People with Disabilities UNCRPD⁵. This submission by the NAI refers to and supports these calls for broader reform but mainly focuses on recommendations to specifically address the applicability and provisions for people with neurological disability within the Act.

Summary of Main Recommendations

Part 1 of the Act should be incorporate a more inclusive definition to reflect the reality of neurological conditions as a leading cause of disability, that these conditions can occur at any time across the life course and that the needs of people with neurological conditions can change over time.

¹ Overview of People Engaging with Disability Services 2025 (2025) National Ability Supports System, Health Research Board

² O Mahony, C. and Quinlivan S. (2026) Reflecting Reforming, Reimagining: Lived Experiences, Rights and Reform Priorities for the Disability Act 2005 at Twenty One Years (University of Galway)

³ Report on Pre Legislative Scrutiny of the General Scheme of the Disability (Amendment) Bill 2025 (April 2026) Joint Oireachtas Committee on Disability Matters

⁴ National Human Rights Strategy for Disabled People 2025-2020 (2025) Department of Children, Disability and Equality.

⁵ UN Convention on the Rights of People with Disabilities (2006) United Nations

Part II of the Act, the assessment of need, presents significant challenges for children with neurological disability because of the difficulty of securing specialist neurological multidisciplinary expertise and input, the lengthy waiting times and backlogs, and the lack of a statutory entitlement to services based on the assessment.

The current age limit for the rollout of the Assessment of Need continues to significantly limit the provisions of Part 2 of the Disability Act for people with neurological disability, reflecting the adult onset of many neurological disabilities.

Part III of the Act does not take into account the range of ways in which people with neurological disability face barriers to participation which extends beyond physical accessibility

Part IV of the Act, which governs genetic testing and the processing of genetic data, requires significant updating and revision to take account of advances in understanding of genetic conditions and genetic testing and legislative changes since the Act was published.

Part V of the Act, in relation to employment of people with disabilities focuses on public sector targets for employment and does not reflect the needs of people with neurological conditions for greater access to supports and protections to remain in the workplace or, fundamentally, the neurorehabilitation supports to enable employment.

Part VI: The application and implementation of universal design should be strengthened to ensure that the definition and operation of the Act fully reflect the experience of people with neurological disability.

While overall the Act requires substantive revision to reflect Ireland's commitments within the UNCRPD, Articles 19, 25 and 26 are singled out in this submission as areas where people with neurological disability experience significant challenges and barriers to their rights under the UNCRPD.

The review of the Disability Act provides a critical opportunity to move beyond a framework concerned primarily with assessment, service administration and public-sector obligations and establish a rights-based framework in which identified disability-related needs give rise to clear duties to provide, or secure access to, appropriate supports.

For people with neurological disabilities, this would represent a significant shift from a system in which access can depend on geography and service capacity towards one in which the individual's rights, needs, wishes and participation are central.

Introduction

As the national umbrella organisation for neurological charities, the Neurological Alliance of Ireland welcomes this review of the Disability Act as a key opportunity to focus on bringing this legislation up to date and fit for purpose as the key legislative framework underpinning the recognition of, and provision for, the needs of people with disabilities in Ireland.

The current review represents a much needed focus on this legislation in the context of more than two decades of reform and change across disability landscape in Ireland and internationally. The review follows the commitment in the Programme of Government to conduct a comprehensive reform of the Disability Act, and also takes place against the backdrop of the publication of National Human Rights Strategy for Disabled People 2025–2030. This strategy, the first national disability strategy published since Ireland's ratification of the UNCRPD, commits to a whole-of-government approach across five thematic pillars: Inclusive Learning and Education, Employment, Independent Living and Active Participation in Society, Wellbeing and Health, and Transport and Mobility.

The NAI hopes that this current review of the Disability Act will provide a robust legal framework and implementation and monitoring structure to deliver on the commitments set out in the National Human Rights Strategy for Disabled People, to people in Ireland across the entire range of disabilities.

In its role as the national umbrella representing neurological charities, this submission by the Neurological Alliance of Ireland incorporates as its primary focus the aspects where the Act and its implementation need to be reformed to reflect the experiences and requirements of people living with neurological disability. Neurological conditions have been identified by the World Health Organisation as a leading causes of disability and ill health worldwide. According to the Global Burden of Disease, Injuries, and Risk Factors Study 2021⁶, produced in collaboration with the World Health Organisation, neurological conditions were the top contributor to the global disease burden in 2021, ahead of cardiovascular disease, affecting 43% of the world's population, or 3.4 billion people. This burden, measured in disability-adjusted life years, rose by 18% between 1990 and 2021, climbing from roughly 375 million to 443 million years of healthy life lost, driven substantially by population growth and ageing. In Ireland, over 860,000 people, or one in six of the population, are living with a neurological condition, and more than 50,000 people develop a neurological condition each year.

The review of the Disability Act 2005 represents an opportunity to ensure that the needs of the growing population of people with neurological disability are recognised within disability legislation, and that the provisions and operation of the Act address the barriers and challenges they experience.

Part 1 of the Disability Act

The University of Galway report, *The Disability Act 2005 at 21: Reflecting, Reforming, Reimagining*, argues that the Act's definition of disability should be modernised to reflect Article 1 of the UNCRPD rather than its current impairment-focused and restrictive formulation. The report identifies the existing definition as problematic because it requires a substantial restriction on a person's capacity to work or participate in social or cultural life and specifies particular categories of impairment.

⁶ Global Burden of Disease, Injuries and Risk Factors Study (2021) Institute of Health Metrics, University of Washington

The report recommends moving towards a broader, more inclusive definition centered on the interaction between impairment and barriers to full participation.

A revised more inclusive definition is required in order to reflect the reality of neurological conditions as a leading cause of disability, that these conditions can occur at any time across the life course and that the needs of people with neurological conditions can change over time.

Part 2: Assessment of Need

Resource constraints and other issues within the current assessment of need process continue to have a significant impact on children with a neurological disability. As noted by the Joint Committee on Disability Matters at oral hearings earlier this year, evidence points to a system under severe strain: 87% of children did not receive their AON within the legally required six-month timeframe in 2025, and more than 20,000 applications were overdue at year end, driven by workforce shortages and rising demand. The Neurological Alliance of Ireland supports the recommendations of the Committee in calling for disability determination to be applied in a child-centred, rights-compliant way without raising practical access thresholds; for Assessment Officers to have defined clinical qualifications and access to multidisciplinary input; for core procedural safeguards around application closure (written notice, reasons, and reopening rights) to sit in primary legislation rather than regulations; for statutory guidelines to be non-binding, published in full, and laid before the Oireachtas where they affect rights; and for transitional protections ensuring applicants already waiting are not disadvantaged. Their recommendations also call for the Bill to be interpreted consistently with the UNCRPD, for independent review and appeal mechanisms for key decisions, for a funded workforce and service capacity plan to accompany implementation, for regular publication of waiting-time and outcome data, and for formal reviews of the legislation's operation.

The National Human Rights Strategy for Disabled People 2025–2030 commits to reducing waiting lists for both therapy services and Assessments of Need, and to improved early intervention for children with complex needs. The current Assessment of Need (AON) is intended as a pathway to support. However, statutory timeframes are routinely breached, with children with neurological conditions waiting years rather than the legislated months for an assessment to even begin. For a child with a neurological condition, delay can represent a lost window for early intervention at precisely the developmental stage when input has the greatest impact on outcomes.. Access to the multidisciplinary neurospecialist expertise required to make a comprehensive assessment of a child's needs is also a significant issue, given the significant gaps in paediatric neurology, neurodisability and rehabilitation services highlighted within the Model of Care for Paediatric Healthcare in Ireland⁷. The lack of sufficient personnel and infrastructure for the diagnosis and ongoing care of children with neurological conditions also limits the availability and time for specialist input into the assessment of need process.

For children with neurological disability, whose needs are frequently complex, multidisciplinary and time-sensitive, an assessment that documents need but carries no

⁷ National Model of Care for Paediatric Healthcare Services in Ireland (2016) Health Services Executive & Royal College of Physicians in Ireland

entitlement to a service response offers limited practical value, reflecting the consensus from across review reports that the Assessment of Need process carries no statutory entitlement to services.

The existing rollout of the Assessment of Need creates a significant gap for people with neurological disability, with a substantial proportion of neurological disability acquired during adulthood. NAI's 2025 report *The Right Care in the Right Place*⁸, highlights significant gaps in neurorehabilitation services and other specialist supports for adults with neurological conditions. For people who acquire a neurological disability in adulthood, there is currently no equivalent comprehensive statutory mechanism under Part 2 through which those needs can be assessed and identified. This is increasingly difficult to reconcile with the contemporary understanding of disability and with Ireland's obligations under the UN Convention on the Rights of Persons with Disabilities. The Government's decision to review the Disability Act in its entirety provides an opportunity to address this structural gap, that a modern Disability Act must recognise disability across the life course.

Part 3: Accessibility of Public Services and Information

Part 3 places duties on public bodies to ensure accessibility of buildings, services, and information. For people with neurological conditions, barriers to full participation can include cognitive, sensory, communicative, and fatigue-related issues rather than purely physical accessibility. Fluctuating symptoms, fatigue and muscle weakness, memory difficulties, speech and communication impairments, and visual and sensory issues can make it just as difficult to access a public service as physical access, yet these needs are rarely captured in current compliance frameworks or Access Officer training.

The National Human Rights Strategy for Disabled People 2025–2030 commits Government to a cross-government approach to accessibility, including better accessibility of information through enhanced access to digital and assistive technologies. The NAI welcomes this commitment, and submits that Part 3 of the Act must be reformed in line with this policy commitment to give it enforceable, statutory effect.

The review of the Act presents a critical opportunity to broaden the definition of accessibility used throughout Part 3 so that it explicitly recognises non-physical and invisible barriers. This should include a statutory requirement for public bodies to provide information in plain language, easy-read, and multiple formats; to allow flexible or extended timeframes for engagement with services where fatigue or cognitive impairment is a factor; and to train frontline staff and Access Officers in recognising and responding to neurological and invisible disabilities. The current model of accessibility auditing, which tends to rely on physical access audits alone, should be replaced or supplemented with a broader accessibility audit framework that considers cognitive accessibility, communication accessibility, and the accessibility of digital services, given the increasing move of public services online.

Part 3 should also place a clearer and more enforceable obligation on public bodies to consult directly with people with lived experience of neurological disability and

⁸ The Right Care in the Right Place: Access to Services for People with Neurological Conditions Across Ireland (2025) Neurological Alliance of Ireland

representative organisations when designing or reviewing services, rather than relying solely on generic disability access standards.

Part 4: Protection of Genetic Data

Genetic neurological conditions encompass a wide range of rare and inherited disorders affecting the brain, spinal cord, peripheral nerves and muscles. Many are complex, lifelong conditions associated with significant disability and support needs. Understanding of genetics and the clinical application of genomic information have advanced considerably since the Disability Act 2005 was enacted. Part 4 of the Act, which introduced specific protections concerning genetic testing and the processing of genetic data, was an important first step in protecting people from genetic discrimination. However, almost two decades of scientific, technological, health policy and legislative change mean that these provisions now require substantial review and modernisation.

The need for reform is reinforced by Ireland's National Strategy for Accelerating Genetic and Genomic Medicine in Ireland⁹, published in 2022. The Strategy establishes a national framework for developing a patient and family-centred genetics and genomics service, with an emphasis on equitable access across the country and across the lifespan, strong governance, secure data infrastructure, research and innovation, and trusted partnerships. It specifically recognises the importance of aligning genetic and genomic consent arrangements with Part 4 of the Disability Act, the Data Protection Act 2018, the Health Research Regulations and assisted decision-making legislation. The review of the Disability Act should therefore consider Part 4 not in isolation, but as part of the wider national framework developed for genetics and genomics in Ireland.

Section 41 of the Disability Act defines “genetic data” as data relating to a living person derived from genetic testing of that person. “Genetic testing” is defined by reference to testing undertaken to confirm an existing symptomatic disease, establish a genetic predisposition or susceptibility to disease, or identify a carrier of a disease. Section 42 provides protections concerning consent and information and prohibits the processing of genetic data in specified circumstances relating to employment, insurance and life assurance, health or health-related insurance, occupational pensions and other pension arrangements, and the mortgaging of property. These protections remain highly relevant to people living with, or at risk of, genetic neurological conditions. Predictive testing can generate life-changing information about an individual's future health and may also reveal information with implications for siblings, children and other relatives.

The National Genetics and Genomics Strategy makes clear that genomic medicine is increasingly concerned with the use of genomic information across clinical care, research and service development, rather than with isolated genetic tests. The Strategy envisages improved access to genomic testing, strengthened laboratory infrastructure, secure genomic data storage and the development of a national service capable of using genomic information to improve diagnosis and treatment. It also identifies the importance of carefully controlled access to genetic information from patients and families who consent,

⁹ National Strategy for Accelerating Genetic and Genomic Medicine in Ireland (2022) Department of Health

particularly in supporting research, diagnosis of rare conditions and access to emerging therapies.

The framework in Part 4 therefore needs to be considered against the substantial development of genomic medicine since 2005. Whole-genome and whole-exome sequencing, increasingly sophisticated variant interpretation, genomic screening, non-invasive prenatal testing and large-scale genomic research now form part of the wider landscape. Genetic information may also be generated incidentally through clinical care or research, stored in biobanks, linked with other datasets, or used to generate further inferences about an individual's health and disease risk. The statutory definition of genetic data should therefore be reviewed to ensure that it is sufficiently broad and technology-neutral to remain effective as genomic medicine develops.

The familial nature of genetic information also requires greater recognition. Genetic information is not necessarily information solely about the individual from whom a sample is taken. A genetic finding may have implications for biological relatives who have never undergone testing themselves. This is particularly relevant to inherited neurological conditions, where a person's diagnosis or genetic result can have implications for the health risks and reproductive choices of relatives across generations. The review should therefore consider whether the existing legislative framework provides sufficient protection against the use of family history or other inherited-risk information to the detriment of individuals or their relatives. This is consistent with the National Genetics and Genomics Strategy which recognises that genomic information can have implications extending beyond the individual patient and that trusted partnerships between patients, clinicians and researchers are essential. The review should therefore consider whether existing legislation adequately reflects the distinctive familial nature of genomic information and provides appropriate safeguards where information about one person may reveal information about biological relatives.

Part 4 must also now be considered alongside the General Data Protection Regulation (GDPR) and the Data Protection Act 2018. Genetic data is recognised as a special category of personal data under Article 9 GDPR, alongside health data, and is subject to additional safeguards. The Disability Act itself was amended in 2018 to update references within Part 4 to the GDPR and to the contemporary meaning of “processing”. However, the substantive architecture of Part 4 remains rooted in the framework established in 2005. The review should therefore examine whether the interaction between the Disability Act's specific genetic protections and the wider data protection framework is sufficiently clear and effective for individuals, healthcare professionals, researchers, employers, insurers and other data controllers.

This need for clarity is particularly important as Ireland develops national genomic infrastructure. The National Genetics and Genomics Strategy identifies secure data storage, appropriate governance and controlled access to genomic information as essential components of the national service. Ireland's participation in the European 1+ Million Genomes initiative and subsequent development of the Genome of Ireland project further demonstrate the increasing importance of genomic datasets for research and clinical development. The Disability Act review should therefore consider whether its protections

remain sufficiently clear where genetic information forms part of national or international genomic infrastructure and is used for both clinical and research purposes.

For people with genetic neurological conditions, this distinction is particularly important because genetic information is increasingly part of longitudinal clinical records, research datasets and biobanks rather than existing simply as an isolated genetic test result. Genetic information may be collected at different points in a person's life, interpreted differently as scientific knowledge develops and combined with other clinical, imaging and health information. The review should therefore consider protections relating to the secondary use of genetic information, data linkage, re-identification, retention, sharing and use for purposes beyond the original reason for which information was collected.

The review should also consider the distinction between genetic data and information that can be inferred from genetic or health datasets. Modern genomic analysis can produce information about disease susceptibility, carrier status, familial relationships and likely future health risks. Artificial intelligence and machine-learning technologies can increasingly analyse genetic, clinical, biomarker and neuroimaging data and generate new predictions or classifications about individuals. The statutory framework should be sufficiently future-proofed to address not only information directly obtained from a genetic test but also relevant genetic information and inferences generated through the analysis of genomic and health datasets. The University of Galway's 2026 review of the Disability Act specifically identifies updating protections relating to genetic testing and emerging technologies such as artificial intelligence as a reform priority. The increasing use of AI and machine-learning technologies in genomic analysis, variant interpretation and the analysis of health, biomarker and neuroimaging data creates potential risks relating to profiling, inference, re-identification and discriminatory decision-making. These issues could not have been anticipated when Part 4 was enacted in 2005.

Research presents another important area for consideration. Health research involving genetic and genomic information is now subject to the GDPR, the Data Protection Act 2018 and the Health Research Regulations 2018, creating a broader regulatory framework than existed when Part 4 was enacted. The National Genetics and Genomics Strategy additionally identifies research and innovation as integral to the development of genomic medicine and emphasises the importance of carefully controlled access to genomic information from patients and families who consent. The review should examine whether the interaction between these frameworks is sufficiently clear for people participating in genetic and neurological research and whether individuals are adequately informed about future uses, secondary uses, data linkage and the potential familial implications of genomic findings. This is particularly relevant to neurological research, where relatively rare conditions can require international collaboration and the pooling of data across research studies, clinical services and biobanks. The review should consider whether participants are provided with clear and accessible information about how genetic information may be stored, shared, linked and used in future research, and what safeguards apply where information is transferred or combined with other datasets.

The accessibility of information and consent processes should also be explicitly addressed. People with neurological conditions may have cognitive, communication or other

accessibility requirements. Information about genetic testing, genetic counselling, data processing and research participation must therefore be provided in accessible formats and in a manner that enables meaningful understanding and decision-making. Consent should be meaningful and informed rather than simply a formal requirement. The review should ensure that the operation of Part 4 is consistent with the broader principles of accessibility, supported decision-making and respect for individual autonomy.

This is also consistent with the National Genetics and Genomics Strategy, which places patient empowerment and support at the centre of the future service and recognises the complexity of genomic testing and decision-making. The Strategy identifies the need for appropriate approaches to consent, including consideration of vulnerable groups, and for national guidance that supports good governance of consent, confidentiality, research and data use. The Disability Act should provide a sufficiently strong statutory foundation for these principles.

The potential for discrimination also extends beyond traditional employment and insurance contexts. As health and genomic data become increasingly important to research, healthcare planning, service development and data-driven decision-making, the review should consider whether existing protections adequately address emerging forms of profiling or differential treatment based on genetic or inferred health characteristics. This is particularly important for people with genetic neurological conditions, for whom a genetic diagnosis or risk may precede the development of symptoms or disability by many years.

The review of the Disability Act should therefore treat Part 4 as an area requiring substantial modernisation and alignment with the national genetics and genomics framework.

Given the fundamental and potentially lifelong consequences of genetic information, serious consideration should also be given to whether the protections currently contained in Part 4 would be better supported through a comprehensive and dedicated legislative framework for genetic and genomic privacy and non-discrimination. At a minimum, the review should ensure that protections contained in the Disability Act remain visible, understandable, enforceable and accessible to the people they are intended to protect.

Part 5: Employment of Persons with Disabilities in the Public Service

Part 5 of the Disability Act 2005 governs the employment of people with disabilities in the public service. It requires public bodies to promote and support the employment of people with disabilities, provides for statutory employment targets, monitoring and compliance arrangements, and provides for codes of practice and measures to support the recruitment and employment of people with disabilities. The statutory minimum employment target, originally set at 3%, has since increased to 6% from 2025.

However, the employment provisions of the Disability Act remain predominantly framed around recruitment, employment targets and compliance, rather than the full employment lifecycle of a disabled person. This is particularly significant for people with neurological

disabilities. Neurological conditions are frequently acquired or diagnosed during adulthood, including while a person is already in employment. Conditions may also be fluctuating or progressive and can give rise to combinations of physical, cognitive, communication, sensory and fatigue-related difficulties. The impact on employment can therefore change over time and may require adjustments to duties, working hours, work environments or patterns of work.

The evidence from the Neurological Alliance of Ireland's 2024/2025 My Neuro Survey¹⁰ demonstrates the scale of this issue with 43% of respondents reported that they had stopped working because of their neurological condition. The survey also found that more than 27% of respondents had experienced discrimination at work because of their neurological condition, while one in five reported leaving their job because of their employer's actions or inactions. These findings indicate that employment loss cannot simply be understood as an inability to work arising from a medical condition; workplace practices, the availability of reasonable accommodation and access to appropriate supports can also materially affect whether a person is able to remain in employment.

The findings of the University of Galway review of the Disability Act 2005 further support the need to move beyond a narrow focus on employment targets towards a rights-based framework addressing the retention, progression and participation of disabled people in employment. The review identifies the need for reform of the Act to reflect contemporary disability rights standards and the UN Convention on the Rights of Persons with Disabilities, highlighting that a revised Disability Act should explicitly recognise the right of people with disabilities to work on an equal basis with others, consistent with Article 27 of the UNCRPD, place greater emphasis on retention and career progression as well as recruitment. This should include a statutory framework requiring public bodies to demonstrate not only that they meet employment targets, but that they have effective measures in place to retain employees who acquire a disability, provide timely and effective reasonable accommodation, support return to work following illness or disability, facilitate career development and progression, and prevent discrimination and disadvantage in the workplace.

This is particularly important for neurological disability because people may leave employment not because they are unable or unwilling to work, but because appropriate supports, reasonable accommodations, neurorehabilitation or flexible working arrangements are unavailable or are introduced too late. The NAI survey evidence, including the finding that one in five respondents had left their job because of their employer's actions or inactions, reinforces the importance of addressing these structural and workplace barriers.

The revised Act needs to align with, and provide a legislative basis for, the National Human Rights Strategy for Disabled People 2025–2030, which identifies employment as a specific pillar and commits to maximising meaningful employment opportunities in the public and civil service, promoting hiring and career advancement in the private sector, and providing the right supports at the right time for disabled people to access or return to work.

¹⁰ My Neuro Survey: Research Findings Report (2025) Neurological Alliance of Ireland

Part 6: Centre for Excellence in Universal Design

Part 6 of the Disability Act 2005 established the Centre for Excellence in Universal Design (CEUD) within the National Disability Authority. The legislation introduced a broad statutory definition of universal design, encompassing the design of environments, products, services and electronic systems so that they can be accessed, understood and used by people regardless of age, size, ability or disability. Importantly, the statutory definition is not limited to physical or sensory disability; it expressly encompasses physical, sensory, mental health and intellectual abilities or disabilities.

The application and implementation of universal design should be strengthened to ensure that this broad statutory definition fully reflects the experience of people with neurological conditions. Neurological disability can have a wide ranging impact: affecting movement and coordination, vision and visual processing, speech and communication, cognition, memory, concentration, executive functioning, sensory processing and energy levels. Symptoms may also fluctuate considerably over time and may be invisible to others.

For people with neurological conditions, accessibility therefore cannot be understood solely in terms of physical access. A building may be physically accessible while a service remains inaccessible because information is difficult to understand, processes require prolonged concentration or memory, waiting times are excessive, communication is rushed, digital interfaces are complex, or the environment creates sensory overload. Fatigue can also mean that an otherwise accessible service becomes inaccessible if it requires lengthy journeys, multiple appointments, prolonged waiting or the completion of complex administrative processes.

The existing principles of universal design already provide a basis for addressing many of these issues. CEUD guidance, for example, recognises the importance of simple and intuitive use, flexibility in the user's pace, minimising unnecessary complexity and designing for people with cognitive and memory impairments. Its guidance on accessible forms explicitly recognises that completing forms can impose significant cognitive load and that users with memory difficulties may require information and labels to remain visible throughout a task. The European Accessibility Act framework also now provides a more explicit basis for addressing cognitive accessibility, including requirements relating to understandable information, multiple modes of communication and products and services designed for people with limited cognition.

The revised legislation should therefore strengthen the statutory role of the CEUD and require it to promote a comprehensive, evidence-based and participatory approach to universal design. This should include recognising the particular barriers associated with neurological conditions.

The Revised Act should also clarify the relationship between universal design and reasonable accommodation. Universal design should be used to remove barriers for the widest possible range of users at source, but it cannot eliminate the need for individual adjustments. For a person with a neurological condition, reasonable accommodation may still include additional time, alternative communication methods, quieter environments,

flexible appointment arrangements, assistance with complex processes or alternative methods of accessing a service.

There is also a need to strengthen the research, monitoring and accountability functions underpinning universal design. The legislation currently requires the Centre to contribute to the development and promulgation of standards, support the development of standards for electronic systems, promote education and training, develop knowledge and awareness, and undertake practical and theoretical work specified by the Minister. The revised Act should build on these functions by giving the CEUD a more explicit role in researching accessibility experiences, evaluating the implementation and effectiveness of universal design standards, identifying persistent gaps and reporting publicly on progress. This should include the systematic collection and publication of evidence on the accessibility experiences of different disability groups, including people with neurological conditions. Evaluation should consider not simply whether a standard or service is technically compliant, but whether people can actually access, understand, navigate and use the service independently and with dignity. This would also address an important gap identified by the University of Galway review: the need to move from a system based predominantly on statutory responsibilities and administrative processes towards one characterised by meaningful participation, implementation and accountability.

The revised Disability Act should therefore position universal design not simply as a set of technical standards, but as an ongoing, evidence-based and participatory process of removing barriers. For people with neurological conditions, this would help ensure that accessibility encompasses not only whether a person can physically enter a building or use a website, but whether they can understand information, communicate effectively, manage the cognitive and sensory demands of a service, navigate processes at an appropriate pace and participate on an equal basis with others.

Additional Feedback

Articles 19, 25 and 26 of the UNCRPD Health, Independent Living and Rehabilitation

The current review of the Disability Act 2005 should be ambitious in bringing Irish disability legislation into much closer alignment with Ireland's obligations under the UN Convention on the Rights of Persons with Disabilities (UNCRPD). Articles 19, 25 and 26 are singled out for particular attention in this submission as they have a significant interdependent impact on other rights across the UNCRPD. For people with neurological disability access to timely diagnosis and specialist healthcare, neurorehabilitation, personal assistance, home support, assistive technology, accessible housing and community-based services will determine whether they can remain living at home, participate in education or employment, maintain relationships and exercise choice and control over their lives.

A significant weakness in the current legislative framework is that, while Ireland has developed a range of strategies, policies and service commitments relevant to these rights, the Disability Act does not establish comprehensive, enforceable entitlements to the services and supports required to realise them. This creates a substantial gap between

Ireland's obligations under the UNCRPD and the practical rights available to people with disabilities.

Article 25 : Health

Article 25 recognises the right of persons with disabilities to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. It requires States Parties to provide the same range, quality and standard of healthcare available to others, while also providing health services specifically required because of disability, including early identification and intervention and health-related rehabilitation. Importantly, services should be available as close as possible to people's own communities, including in rural areas.

For people with neurological conditions, access to healthcare can encompass a continuum of care extending from timely diagnosis and specialist treatment, through to rehabilitation and long-term specialist supports in the community. The current system remains fragmented and access is highly variable according to geography, condition and service. NAI's 2026 report *Towards an Equitable Integrated Neurology Service for Ireland*¹¹, based on a nationwide audit of neurology services, identified significant gaps in neurological healthcare with geographic inequity reported as a significant issue. A rights-based framework needs to move beyond a model in which services are provided where capacity happens to exist. Identification of a health or rehabilitation need should lead to timely access to an appropriate service, regardless of where a person lives or which neurological condition they have.

The revised Disability Act should place a clear duty to progressively ensure equitable access to specialist disability-related healthcare with particular attention to regional disparities, waiting times and continuity of care.

Article 19 : Living independently and being included in the community

Article 19 establishes the equal right of persons with disabilities to live independently and to be included in the community. It requires States Parties to ensure that people can choose where and with whom they live and have access to the range of in-home, residential and other community support services, including personal assistance, necessary to support living and inclusion in the community and to prevent isolation or segregation.

The Ombudsman's 2021 investigation, *Wasted Lives: Time for a better future for younger people in Nursing Homes*¹², examined the circumstances of people under 65 living in nursing homes and notes that a majority are living with neurological conditions. The Ombudsman concluded that the system needed to move away from a medical model of disability towards a person-centred and rights-based approach consistent with the UNCRPD. The report made

¹¹ Towards an Equitable, Integrated Neurology Service for Ireland (2026) Neurological Alliance of Ireland

¹² Wasted Lives: Time for a Better Future For Younger People in Nursing Homes (2024) Office of the Ombudsman

19 recommendations addressing issues including funding, informed consent, quality of life, access to services, navigating the system, policy and human rights.

In September 2024, the Ombudsman reported that 81 people had been supported to move to more appropriate accommodation, with a further 17 moves at an advanced stage, but that more than 1,200 people remained in nursing homes who had not had that opportunity. The Ombudsman specifically highlighted the risk that a lack of funding would continue to prevent people from moving to more appropriate living arrangements.

The Government's Action Plan for Disability Services 2024–2026 recognises the need to increase support for people with disabilities to access supported independent living and to provide supports to live at home, with a stated objective of phasing out long-term nursing home care for younger people with disabilities. It also includes commitments relating to personal assistance, home support, respite and community-based residential provision.

The revised Disability Act should therefore establish independent living and inclusion in the community as statutory objectives, supported by clear duties on public bodies. Access to supports should be based on an individual's assessed needs, wishes and preferences rather than the availability of a particular service locally.

The legislation should also recognise that independent living is not synonymous with living alone. It means having genuine choice and control over where and with whom a person lives and having access to the supports necessary to participate in community life on an equal basis with others.

Article 26: Habilitation and Rehabilitation

Article 26 requires States Parties to organise, strengthen and extend comprehensive habilitation and rehabilitation services and programmes. These should be based on multidisciplinary assessment of individual needs and strengths, begin as early as possible, support inclusion and participation, and be available as close as possible to people's communities, including rural areas. Article 26 also specifically recognises the importance of professional training and assistive devices and technologies.

Article 26 is particularly important for people with neurological disabilities because of the importance of access to neurorehabilitation as an enabler for exercising other rights under the UNCRPD. Appropriate rehabilitation can determine whether a person can remain living in their own community, return to work or education, maintain relationships and participate in community life.

Ireland has recognised the importance of rehabilitation through the National Strategy & Policy for the Provision of Neuro-Rehabilitation Services in Ireland¹³ and its subsequent implementation framework. The strategy envisages integrated, person-centred

¹³ National Policy and Strategy for the Provision of Neurorehabilitation Services in Ireland (2011) Department of Health

rehabilitation provided at the lowest appropriate level of complexity and as close to home as possible, supported by population-based managed clinical rehabilitation networks.

However, the existence of a national strategy or implementation plan does not itself create an enforceable legal entitlement to neurorehabilitation, and it is important to note that the National Neurorehabilitation Strategy only addresses the needs of individuals over 18 years. Implementation of Article 26 cannot be achieved solely through the development of strategies or the incremental expansion of services. A rights-based approach requires a system capable of responding to identified individual need in a timely manner.

The revised Disability Act should therefore establish a statutory framework for access to rehabilitation based on assessed individual need and establish clear accountability for monitoring unmet need, waiting times and regional inequalities in access to rehabilitation and other disability-related health services.

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