IRELAND'S **AUTISM** CHARITY

March 2026

AsIAm Submission to the Joint Committee on Disability Matters on the General Scheme of the *Disability (Amendment) Bill 2025*

About AsIAm

AsIAm is Ireland's Autism Charity. Founded in 2014, AsIAm advocates for an inclusive society for Autistic people that is accessible, accepting and affirming. We work to support the Autistic community and our families throughout the lifecycle to fully engage in Irish life and build the capacity of society to facilitate true inclusion. This is achieved through the programmes of support we offer and our advocacy work. AsIAm provides a range of programmes through our national and regional based activities and programmes.

AsIAm is a Disabled Person's Organisation (DPO) as we are Autistic led, informed by the experiences of Autistic people, and more than half of our staff and board are Autistic or have other differences or disabilities. AsIAm's work focuses on advancing the rights of Autistic people across Irish society. We use a rights-based, Neuro-affirmative approach in all our work, supporting Autistic people across all supports within the organisation. AsIAm is also a founding member of the DPO Network – an alliance of five national DPOs who collectively advocate for the rights of Disabled people and to advance the full implementation of the UNCRPD in Ireland**,** across all our laws and policies.

About Autism

Autism is a lifelong developmental difference or disability which relates to how a person communicates and interacts with others and how they experience the world around them. In keeping with our community's preferences, AsIAm uses identity-first language ("i.e. *Autistic person*") throughout this submission to reflect that their experience of autism is a core part of their identity and central to their experience of living in Irish society. Further details about Autistic people's language preferences can be found in our Language Guide here**.**

Introduction

AsIAm welcomes the opportunity to make this submission to the Joint Committee on Disability Matters as part of its pre-legislative scrutiny of the General Scheme of the Disability (Amendment) Bill 2025. The proposed reforms to Part 2 of the Disability Act 2005, governing the Assessment of Need (AON) process, represents a particularly important and consequential legal development for Disabled children and young people and families.

The discussion comes at a critical moment in Ireland's disability policy landscape, particularly considering Ireland ratifying the *United Nations Convention on the Rights of Persons with Disabilities* *(UNCRPD)*, and it's *Optional Protocol* in 2024. The State has undertaken binding legal obligations to reform domestic laws and systems that govern the rights of Disabled people and how services are allocated to ensure that these comply with the UNCRPD. In this context, reforms to the Assessment of Need process are not merely procedural but greatly impact how Disabled people and families access a range of human and constitutional rights.

This submission sets out and examines the proposed structural implications of the Disability (Amendment) Bill 2025, in relation to the proposed amendments of Section 7, 8, 9 and 21 of the Primary Act. These concerns are grounded in the previously struck down interpretations by the Courts in 2023, regarding access to an Assessment of Need under the Disability Act

2005. Our concerns also centre on “efficiency” replacing rights based-comprehensive assessments for the disabled community.

During this oversight process, it is important for the Joint Committee on Disability Matters to engage in this pre-legislative scrutiny through the lens of current debates and narratives, in a context of rising misinformation about Autism; **91% of our community reported a growth in misinformation on Autism in 2025.**[1] Unfortunately, this misinformation both nationally and internationally has not been immune to undermining both the need for and validity of an autism diagnosis. Equating an identification of Autism with access to resources or questioning a person’s need for support or accommodations are not only deeply stigmatising but fail to grasp the transformational impact access to an Autism diagnosis can have for an Autistic individual and the opportunity to present to the State to support and affirm people *“as they are”* rather than a lifetime of misdiagnosis, mistreatment, masking, isolation and exclusion.

Considering this, we see a push by relevant Departments to remove the requirement of a diagnosis to access such supports. We believe that taking this action in the absence of also rolling out an inclusive education system in line with the UNCRPD is misguided and will have foreseen consequences when it comes to future school planning, and devastating consequences for our community as a result. AsIAm is not averse to reform of the Assessment of Need, in fact we welcome reform. However, reform should not come at the expensive of a quality based comprehensive assessment model.

Current Context

At present, access to an Assessment of Need and to supports is under significant pressure, creaking from the pressures arising from a lack of resources and growing waiting lists. At

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[1] AsIAm, Same Chance Report 2025, https://cdn.prod.website-files.com/6537ebfefba7b3c24a18e646/67e572276f39ff1d6d830135_Version%203%20Digital%20Full%20AsIAm%20Same%20Chance%20Report.pdf (accessed 26 Jun 2025).

present, AONs are under severe strain, and we are seeing many Autistic children slipping through the cracks which has a negative and regressive impact on children seeking supports.

The statutory timeframe requires that an Assessment of Need commence within three months of application and be completed within a further three months. In practice, these timeframes are routinely breached. Over 90% of children who are part of the AON applicants are not seen within the six-month period. The average waiting period for an Assessment of Need is over 27 months. As of December 2025, there are over 20,000 children who are overdue an Assessment of Need.

This speaks to a deep-rooted crisis within the system – many families who engage with our services feel like they are being blamed for pressuring the system by asking for the supports that their child is entitled to. But they are not responsible for Clinical shortages or the lack of resourcing that hinders the AON system from functioning effectively. We can all agree that these are important reasons why reform needs to take place to make a better system.

Families report long delays, inconsistent reporting, lack of transparency in the decision-making processes, and lack of clarity over what happens after an Assessment of Need is conducted.

While the Disability Act creates a legal right to assessment, it does not create a corresponding right to timely access to the services identified in the assessment report. As a result, children may receive confirmation that they have support needs without any realistic pathway to accessing these supports. Families and individuals can often be redirected to Children's Disability Network Teams (CDNTs), but we know many of our CDNT teams are not fully staffed, with the vacancy rate now at 18%. This undermines the right to timely assessments and supports, creates further uncertainty and distress for families, and impedes on public confidence in the AON's ability to effectively identify needs and deliver supports.

Increasingly, families who can afford to do so are turning to private assessments and supports, and the HSE has been allocated funding for accessing private assessments to help address these waiting lists. Whilst we do acknowledge that this is somewhat helpful in alleviating immediate backlogs within the system, it is still a sticking plaster solution that does not adequately address the structural issues within the AON process and reinforces socio-economic barriers to accessing supports within the healthcare system.

This speaks to why reforms to the Disability Act are needed, but this reform must not come at the expense of providing comprehensive assessments for those who are seeking such support. It also must not further erode or devalue an Autism diagnosis, which is a disability and should be protected as same.

Assessment of Need Under Current Legislation

In 2020 the HSE introduced a Standard Operating Procedure (SOP) which gave effect to the Preliminary Team Assessment (PTA). The Preliminary Team Assessment (PTA) was a controversial 2020 initiative, consisting of a 1-hour observation and 30-minute parent consultation, designed to replace comprehensive diagnostic assessments for children's disability needs. This was introduced to mitigate against the ever-growing waitlist for the Assessment of Need. A High Court ruling in March 2022 deemed the PTA non-compliant with the primary Disability Act, 2005, forcing a return to a more comprehensive, diagnostic-focused assessment process. The Courts in their determination highlighted how the Assessment process was *“integral to how the State discharges its duties to vindicate the rights of children with disabilities”*. It is from this mantra and position the State should be coming from when it comes to an Assessment of Needs.

The Assessment of Need process is a vital support for our community, as it is a key mechanism in which Disabled people are assessed and supported, to ensure that they are

understood, have their experiences recognised and validated. For many families, the AON process is their first formal interaction with the State in seeking understanding, validation and support for their child, and their experiences with this process shapes both access to supports for their child and their wider trust in public services and institutions. A rights-based, neuro-affirmative assessment process
can open and facilitate acceptance, wellbeing and participation. Inversely, a restrictive, bureaucratic assessment process can perpetuate isolation, exclusion and discrimination as was seen under the previous Preliminary Team Assessment.

Disabled children and families consistently tell us that they face structural barriers to accessing their statutory right to an Assessment of Need, to therapies and
services identified within their respective service statements. These include long waiting lists, lack of transparency, and follow-through on addressing the child's support needs. Many families apprise our offices on the exclusionary practices within the health, social care, disability and education systems, which fall short of meeting a Disabled child's needs or vindicating their rights. It is within this context we welcome reform of the Assessment of Needs process.

The proposed amendments to the *Disability Act* offer an opportunity for the Government to take leadership and strengthen disability rights and align our laws and systems with our international human rights obligations. However, it would be remiss if we did not highlight the potential risks highlighted by these reforms which can make it even harder for Disabled children to be supported to fully participate in society. These risks include raising the eligibility criteria to access supports, weakening ethical and clinical professional standards, or expanding Ministerial discretion around the provision of supports without appropriate oversight or accountability. We wish to use this submission to explore these issues in more detail and to offer recommendations which we believe would make the Assessment of Need process fairer and more supportive of Disabled children and young people.

Reforms to the Disability Act Must Be Rooted in the UNCRPD

The *Disability Act 2005* predates Ireland's ratification of the UNCRPD and reflects the Medical Model of Disability approach, which prioritised "treatments" or "cures" of their access needs. Section 2 of the 2005 Act defines disability as *" a substantial restriction in the capacity of the person to carry on a profession, business or occupation in the State or to participate in social or cultural life in the State by reason of an enduring physical, sensory, mental health or intellectual impairment"*[2]. This definition falls far short of reflecting Article 1 of the UNCRPD, which states that *"Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others."*[3] In moving towards a human rights understanding of disability which reflects the Social Model of Disability, the UNCRPD reflects a paradigm shift, as it sees barriers arising from the person's disability or impairment emanating from the person's interaction from structural, attitudinal and environmental barriers they face on a day-to-day basis.

Reforming the Assessment of Need process without also aligning the underlying definition of disability with the UNCRPD risks entrenching a model which is inconsistent with Ireland's obligations under the Convention. Section 7 should particularly reflect an understanding of disability which is consistent with the UNCRPD. Any retention or reinterpretation of the *"substantial restriction"* threshold risks excluding children whose needs are real and significant but do not meet an arbitrarily high or narrowly interpreted benchmark.

Article 7 of the UNCRPD obliges States to ensure that children with disabilities enjoy all human rights and fundamental freedoms on an equal basis with other children, with the

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[2] Section 2, Disability Act 2005, Disability Act 2005, Section 2 (accessed 27 Feb 2026).

[3] Article 1, United Nations Convention on the Rights of Persons with Disabilities, Convention on the Rights of Persons with Disabilities | OHCHR (accessed 27 Feb 2026).

best interests of the child as a primary consideration.[4] Article 25 guarantees the right to the highest attainable standard of health without discrimination, including disability-specific services.[5] Article 26 requires States to organise and strengthen habilitation and rehabilitation services that enable full participation and independence.[6] To meet these obligations in practice, any Assessment of Needs process needs to ensure that a child's support needs are identified as early as possible, that they have timely access to assessment and to the developmental and therapeutic services identified by the assessment, and that the child's dignity and autonomy is respected, and is flexible to meet their support needs and evolving capacities.

An Assessment of Need Process Must Be a Pathway to Accessing Support

A key challenge highlighted by many community members who access the Assessment of Need process is that while the Disability Act creates a legally enforceable right to an assessment, it does not create the same right to the timely provision of services identified through the assessment. This has contributed to escalating demand for assessments as the only guaranteed statutory gateway to support. Reform must avoid reframing assessment as a way for the HSE to manage families seeking to access support. Instead, assessment should function as part of an integrated pathway of support.

Proposed amendments to Section 7 of the Act seek to introduce language around initial determinations of disability. While there is potential to improve early identification of needs and move toward a more holistic understanding of disability, there is also a risk that such provisions could operate as a re-introduction, in substance and effect,

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[4] Article 7, United Nations Convention on the Rights of Persons with Disabilities, [Article 7 – Children with disabilities | United Nations Enable]() (accessed 27 Feb 2026).

[5] Article 25, United Nations Convention on the Rights of Persons with Disabilities, [Article 25 - Health | Division for Inclusive Social Development (DISD)]() (accessed 27 Feb 2026).

[6] Article 26, United Nations Convention on the Rights of Persons with Disabilities, [Article 26 - Habilitation and rehabilitation | Division for Inclusive Social Development (DISD)]() (accessed 27 Feb 2026).

of the Preliminary Team Assessment (PTA) model which was struck down by the High Court in 2022.

Any changes to the Disability Act should ensure that:

- Any *"initial determination"* cannot serve as a barrier to accessing an autism assessment or follow-on support where clinically or educationally appropriate.
- Set out the appropriate qualifications of Assessment Officers who will make an "initial determination" of disability.
- The threshold for accessing autism assessments is not raised in practice.
- The assessment process remains comprehensive and multidisciplinary with involvement of appropriate clinical professionals where required.
- The purpose of assessment remains identification of a child's access needs and planning and delivery of necessary supports.

Clarity on Professional Qualifications and Standards

Proposed amendments to Section 8 of the Act seek to expand the pool of clinical professionals who would be qualified to conduct assessments and deliver supports. While this may increase capacity and reduce waiting times, it also raises legitimate concerns regarding maintaining ethical and professional standards, which has been highlighted by a number of professional bodies representing clinicians working to support Autistic and Disabled people.

Disabled people and families consistently emphasise the importance of assessments being conducted by professionals with the relevant clinical and professional expertise in autism and neurodivergence. Any dilution of standards risks Disabled people being misdiagnosed, delayed support and the impact of inadequate supports.

Any reforms to the Disability Act should therefore:

- Clearly define *"suitable professionals"* in primary legislation or through robust statutory safeguards.
- Require the clinician to demonstrate they have sufficient expertise to conduct autism assessments, based on standards set by their professional body.
- Ensure that multidisciplinary assessments are facilitated where clinically indicated.
- Protect the integrity and status of autism assessments and supports, and public confidence in professionals working to support Autistic people.

Safeguarding Autonomy and Informed Consent

Proposed amendments to Section 9 of the *Disability Act 2005* highlight concerns in relation to the family's right to exercise autonomy and provide free and informed consent to a child accessing an autism assessment, and any supports identified on their Assessment Report. Families must receive clear, accessible information about their statutory rights, any information regarding their AON application, what assessments do and the limitations of accessing a diagnosis through the AON process, and the processes involved in accessing assessments and therapeutic supports.

There must be explicit protection against families being pressured inadvertently to withdraw AON applications and any support therein. Informed consent should be required before a clinician can initiate therapies following an autism assessment, and clinical practice should reflect the right of children and families to dignity and autonomy around the process.

Ministerial Discretion

Amendments to Section 21 propose expanding use of statutory guidelines and grants discretionary powers to the Minister to make changes to these guidelines.

AsIAm are concerned that reliance on guidelines risks weakening independent oversight over the AON process and puts Disabled children and families at risk of harm.
The Committee should consider:

- Requiring consultation and active engagement with Disabled Persons Organisations (DPOs), advocacy organisations and professional bodies governing the clinical professions involved prior to issuing guidelines.
- Requiring that guidelines explicitly align with the UNCRPD and clinical best practice.
- Introducing safeguards to protect the rights of Disabled children and families throughout the process and to prevent any dilution of rights by way of secondary legislation;
- Providing for parliamentary oversight by the Oireachtas where any changes to the guidelines materially affect the right to access an autism assessment.

Addressing the Structural Gap Between Accessing an Autism Assessment and Supports

Reform of Part 2 must also acknowledge a wider systemic issue within the Assessment of Need process – children cannot wait for comprehensive legislative reform while the system remains under strain and children still face significant waiting lists to get the supports they need.

While the Committee’s remit is focused on assessments, it is important to recognise that delays to accessing assessments cannot be divorced from wider structural issues within health and disability services to deliver supports to meet the needs of Disabled children and young people. Without more robust monitoring and accountability mechanisms to ensure the delivery of support in a timely manner, any reforms to the assessment process will not resolve the deep-rooted structural issues across the system. We would take the view that the Committee should consider whether stronger guarantees are needed to ensure that when an assessment identifies a child’s support needs, they have timely access to supports, and what changes are necessary for Ireland to meet our international obligations for delivering supports. Reform must not unintentionally or intentionally narrow access or weaken safeguards. Legislation should exist to support community members, not to provide unnecessary delays.

Recommendations

In light of the concerns identified throughout this submission, AsIAm calls on the Joint Committee on Disability Matters to consider the following recommendations as part of its pre-legislative scrutiny of the General Scheme of the Disability (Amendment) Bill 2025.

Reforms should strengthen the rights of Autistic people and families during the Assessment process and when accessing supports, and ensure that assessments offer a pathway to timely access to supports:

Align the Disability Act with the UNCRPD

- Amend Section 2 of the Disability Act 2005 to reflect the definition of disability within Article 1 of the UNCRPD, to officially adopt a human rights, neuro-affirmative approach consistent with the Social Model of Disability
- Revise or remove the "substantial restriction" threshold to ensure that it facilitates Autistic people to exercise the right to access supports following an assessment.
- Ensure that Section 7 reflects a human rights-based approach to disability and does not raise eligibility criteria or thresholds to accessing support.

Safeguard the Right to Accessing Assessments and Supports

- Guarantee that any "initial determination" cannot restrict an Autistic person's right to access a multidisciplinary assessment.
- Ensure reforms do not reintroduce, in substance or effect, the Preliminary Team Assessment model previously found unlawful.
- Provide that assessments are comprehensive, rights-based, person-centred and neuro-affirmative.

- Protect the professional standards of clinical professionals conducting autism assessments and supports

Protect Professional Standards

- Clearly define *"suitable professionals"* by developing robust statutory guidelines in partnership with Autistic people, clinical professionals and their representative organisations and professional bodies.
- Require clinical professionals involved to have direct expertise or training with conducting autism assessments and designate areas of expertise which qualify a professional to conduct these assessments.
- Support the development of National Guidelines for Conducting Autism Assessments across public and private healthcare settings, co-designed with Autistic people, professionals working to support Autistic people and their representative organisations.
- Ensure that psychology is fully regulated and that "psychologist" remains a legally protected title to safeguard public confidence and patient safety and protect professionals who support Autistic people.
- Conduct periodic audits of training and professional standards to ensure alignment with evolving best practice.

Embed Neuro-affirmative Practices

- Require core autism and neurodiversity training for all professionals involved in Assessment of Need processes.
- Mandate ongoing Continuous Professional Development (CPD) in neuro-affirmative practice, informed by Autistic-led research and by the lived experiences of Autistic people.
- Ensure training reflects trauma-informed and rights-based approaches, avoiding outdated or harmful practices which pathologise Autistic people.

- Review and regulate therapies or interventions offered to Autistic people to ensure they are evidence-based, ethical and consistent with human rights standards.

Strengthen Autonomy, Transparency and Wellbeing

- Introduce a statutory obligation to provide clear, accessible information about rights and processes.
- Ensure that families are not pressured to withdraw AON applications and can vindicate their rights throughout.
- Require clinical professionals to obtain free and informed consent before initiating therapeutic interventions.
- Ensure the dignity and evolving capacities of children are respected throughout the Assessment and Support process.

Limit Ministerial Discretion and Strengthen Oversight

- Require consultation with Disabled Persons' Organisations and professional bodies before issuing statutory guidelines.
- Ensure guidelines explicitly align with the UNCRPD and that rights cannont be watered down through secondary legislation.
- Provide for Oireachtas oversight where changes materially affect Autistic people's access to assessment and support.

Develop Binding Timeframes and Address Gaps Between Assessments and Services

- Strengthen enforcement of the six-month statutory timeframe to an Assessment of Needs and ensure that families can access remedies when any delays occur.
- Require transparent reporting processes on watiting lists for Assessment of Needs and any barriers to delivering supports.
- Introduce stronger enforcement and accountability standards to ensure that needs identified in AONs are supported by timely access to supports.

Ensure that Reforms are Adequately Resourced

- Embed workforce planning and capacity building of clinical staff alongside legislative reform.
- Increase investment to expand capacity of Children's Disability Network Teams to meet the needs of our community.