

Inclusion Ireland’s submission to the Joint Committee on Disability Matters’ Pre-Legislative Scrutiny of the General Scheme of the Disability (Amendment) Bill 2025

Introduction

Inclusion Ireland welcomes the opportunity to contribute to the Joint Committee on Disability Matters’ pre-legislative scrutiny of the General Scheme of the Disability (Amendment) Bill 2025.

We support reforms that reduce delays and improve consistency in the Assessment of Need (AON) process for children with intellectual disabilities and their families. However, we are concerned that amending AON in isolation risks reinforcing assessment without follow-through, rather than building a joined-up pathway from early years to young adulthood where assessment is one element of support. We are also concerned that changes focused on timeliness could, in practice, raise the practical threshold for access, dilute assessment quality, or weaken families’ procedural safeguards.

We propose targeted amendments to strengthen UNCRPD alignment and non-regression, protect competence and quality, and hardwire accessible information and fair procedures – especially in relation to statutory guidelines and any “deemed withdrawn” mechanism – reflecting three core priorities: rights alignment, quality, and family protections.

We strongly recommend that Government proceeds without delay to reforming the Disability Act 2005 in its entirety, providing a more fit-for-purpose model where assessment and access to services and supports are provided in a seamless, child and family-centred manner. The issues will continue with AON unless there is deeper and broader reform. This is also true of the wider reform needed in inclusive education. Inclusion Ireland has repeatedly called for joined up thinking across health, social care and education and a fully integrated model of supports for children and young people. If we had a fully inclusive model of education, integrated with health and social care services, the need for assessment reports to access education rights could be removed. Children’s education supports would be provided on a needs-basis. In a fragmented *health and educational system, children and families may be pushed to pursue AON as one of the only mechanisms available to access professional reports.*

Executive Summary

- **We support AON reform to reduce delays, but it must not be treated in isolation.** AON is a starting point, not the support itself, and must connect to a clear pathway of early years supports and inclusive education through to the end of second level – including timely education-related input where needed.
- **UNCRPD alignment and non-regression must be explicit.** Guidelines should be published, consulted on (including disabled people, families and relevant professional bodies), and framed so they cannot narrow access or safeguards in practice; where changes could materially affect access, they should be laid before the Oireachtas.
- **Quality and competence must be protected.** The Bill and/or guidance should set minimum competency and training standards for HSE Assessment Officers and any assessors involved – particularly on intellectual disability, communication/cognitive needs and UNCRPD-consistent disability determination – so expectations are consistent nationwide.
- **Families’ procedural safeguards must be clear and enforceable.** If “withdrawn/deemed withdrawn” closure powers are introduced, they must be narrowly defined and include accessible notice, written reasons, a real chance to re-engage, clear complaints/review routes, and a straightforward mechanism to reopen – alongside transitional protections for families already waiting.

What Families and Our Community are Telling Us

Families’ experience of delayed follow-through is persistent. In our parent experience survey, 95% reported waiting more than six months to access post-assessment services, 83% identified lack of services as a top issue, and 48% cited communication difficulties¹. These barriers sit alongside the scale of unmet demand: as of February 2026, over 20,000 children across the State are overdue an AON² (a 42% year-on increase) – underlining why any reform must strengthen fair procedures and safeguards, rather than introduce new points where children can fall out of the system. In our *1,000 Voices* survey, when families were asked what their top priority was regarding their child’s support, 75%

¹ [Inclusion Ireland \(10th March 2022\), *Progressing Disability Services for Children and Young People: Parent Experience Survey Report*, pgs.4–5](#)

² [Nash, G \(10th February 2026\), ‘Written Answer 937: Disabilities Assessments,’ *Dáil Éireann Debate*](#)

prioritised access to therapies, 24% prioritised both therapies and access to an AON, and 1% prioritised access to AON alone³.

In Inclusion Ireland’s view, the question is not simply whether assessments are faster: it is whether the AON process is fit for purpose, fair, high-quality, and reliably implemented, so that it supports children and does not become another gatekeeping hurdle in an already fragmented system. This matters particularly for children with intellectual disabilities, where communication and cognitive processing needs can shape how disability is recognised, assessed, and supported.

These reforms should also be read through a children’s rights lens: the UNCRC requires the State to ensure children’s survival and development⁴ (Article 6), to provide special care and supports enabling disabled children to live with dignity and participate⁵ (Article 23), and to secure timely access to health services⁶ (Article 24).

Overview of the General Scheme

The General Scheme proposes targeted amendments to Part 2 of the Disability Act 2005:

- **Head 3:** amends the definition of “assessment” to explicitly include determining whether the applicant has a disability and – where disability is established – identifying health and education needs and the services required⁷.
- **Head 4:** clarifies that the NCSE nomination process (section 8[3]) is triggered only once disability is determined and introduces “appropriate expertise” language⁸.
- **Head 5:** inserts a power for an assessment officer to close an application where it is withdrawn or “deemed withdrawn,” intended to address an omission and apply where it becomes impracticable to progress due to lack of engagement and/or a wish to withdraw⁹.
- **Head 6:** enables statutory guidelines (within 6 months) covering interpretation of legal definitions (including “disability”), disability determinations, best practice/standards, operational matters and report preparation; and enables regulations on the circumstances/procedures for closing applications under Head 5¹⁰. The Scheme further states guidelines will be non-binding, will emphasise a “high threshold”, and will include a checklist for disability

³ [Inclusion Ireland \(20th June 2025\), 1,000 Voices, One Message: Invest in Our Rights – Pre-Budget Submission 2026, pg.8](#)

⁴ [United Nations \(20th November 1989\), Convention on the Rights of the Child, Article 6 – Right to life survival and development](#)

⁵ *Ibid*, Article 23 – Disabled children’s right to live a full and decent life with dignity

⁶ *Ibid*, Article 24 – Right to healthcare

⁷ [Department of Children, Disability and Equality \(12th February 2026\), General Scheme of Disability \(Amendment\) Bill 2025, pg.5](#)

⁸ *Ibid*, pg.7

⁹ *Ibid*, pg.9

¹⁰ *Ibid*, pg.10

determination (including “significant difficulty in communication/learning/mobility” and “significantly disordered cognitive processes”¹¹).

- **Head 7:** applies the amendments to applications received where the assessment process has not commenced¹².

Inclusion Ireland supports measures that reduce delay and improve consistency. Our concern is that the Scheme places significant practical power in Head 6 guidelines and Head 5 closure powers. Without stronger statutory safeguards, reforms could produce faster throughput at the cost of fairness, transparency and quality.

Inclusion Ireland’s core concerns

“Guidelines-led” systems can change the lived threshold even if the legal right stays the same (Head 6)

The Scheme states that guidelines will emphasise the “high threshold” and include a checklist setting out the findings that “must be made” for a disability determination¹³.

While DCDE also notes that guidance cannot go outside primary legislation, it also describes guidelines as integrating Standard Operating Procedure (SOP) elements that have not prevented legal errors and non-compliance found by courts¹⁴. This is precisely why the safeguards cannot be left to operational design; if the statutory model relies on guidelines for interpretation, then consultation, transparency, and oversight must be built in.

Head 6 (amending section 21) increases reliance on minister-directed statutory guidelines to shape how the AON process operates in practice, including interpretation of key definitions and the disability determination process. While the Scheme notes guidance cannot exceed primary legislation, the practical reality is that guidance can still drive thresholds, decision-making and consistency on the ground. For that reason, strengthened safeguards are needed to ensure guidelines are developed transparently, aligned with rights and best practice, and subject to meaningful scrutiny where changes could materially affect access to AON.

Additionally, the Scheme places heavy practical weight on guidelines and checklist-based decision supports. In a system already operating under workforce strain (national CDNT vacancy rates were reported at 18% in mid-2025¹⁵), the risk is that guidance designed for consistency can become *de facto* threshold-tightening, unless constrained and transparently overseen. The National Human Rights Strategy for Disabled People

¹¹ *Ibid*, pgs.7, 8, 11 and 12

¹² *Ibid*, pg.13

¹³ *Ibid*, pg.11

¹⁴ *Ibid*, pg.10–11

¹⁵ [Cahill, M \(17th July 2025\), ‘Written Answer 494: Disability Services’, Dáil Éireann Debate](#)

explicitly emphasises DPO representation in delivery and monitoring structures in line with UNCRPD Article 4(3)¹⁶; that logic should apply to Head 6 guidelines through mandatory consultation and publication.

Closure powers (“withdrawn/deemed withdrawn”) risk penalising families navigating barriers (Head 5 and Head 6)

Head 5 is intended to apply where it becomes “impracticable” to progress applications due to lack of engagement and/or a wish to withdraw¹⁷.

In practice, however, non-engagement may reflect barriers that the families of children with intellectual disabilities routinely encounter: inaccessible information, unclear processes, uncertainty about entitlements, and lack of a consistent point of contact. In *1,000 Voices*, one respondent captured this bluntly: “I . . . feel very under prepared . . . the support isn’t there, the training isn’t there . . . if anyone has the manual, I’d really appreciate it.”¹⁸

Another parent described relying on generic social media information as “constant guesswork” without professional guidance¹⁹.

If “deemed withdrawn” is introduced without a strict, accessible, rights-based process, it can become an administrative mechanism that shifts responsibility onto families.

AON reform cannot be siloed from inclusive education and joined-up planning

The Scheme is framed as targeted AON reform. However, the DEY’s own review into the EPSEN Act has underscored AON challenges and the need for cross-government planning across the Education Act 1998, Disability Act 2005, and related legislation²⁰.

Inclusion Ireland’s analysis of the EPSEN Review also highlights a continuing gap in enforceable rights to assessment and supports, and the need for a costed, time-bound Inclusive Education Plan aligned with UNCRPD standards (including General Comment No. 4 on inclusive education²¹).

Inclusion Ireland is also concerned about the practical impact of sequencing NCSE involvement only after disability is determined. In many cases, families pursue AON

¹⁶ [Department for Children, Disability and Equality \(3rd September 2025\), National Human Rights Strategy for Disabled People 2025–2030, pgs.54–55](#)

¹⁷ *Ibid*, pg.12

¹⁸ Inclusion Ireland (20th June 2025), *1,000 Voices, One Message: Invest in Our Rights – Pre-Budget Submission 2026*, pg.13

¹⁹ *Ibid*, pg.9

²⁰ [Department of Education and Youth \(25th June 2025\), Report on the Review of The Education for Persons with Special Educational Needs \(EPSEN\) Act 2004, pgs.23 and 88](#)

²¹ [Committee on the Rights of Persons with Disabilities \(25th November 2016\), General Comment No.4 on the Right to Inclusive Education, CRPD/C/GC/4](#)

because professional reports arising from the process are relied upon to access education supports; delayed educational input risks compounding delay and increasing reliance on private routes. Without addressing these types of fundamental issues, children and families may be further disadvantaged. It is also fair to say that the education assessment may provide valuable information earlier in the process.

For children with intellectual disabilities, AON processes and school inclusion are not separate issues. Many families utilise the AON process to get access to professional reports. Although the AON itself is not necessary, the professional reports which may arise from the AON can be utilised by children and families for access to education supports in special schools and classes. Fragmentation between the health and education systems repeatedly undermines children's participation and family confidence in the system.

Committee recommendations

The Committee's recommendations on AON should be aligned with the National Human Rights Strategy for Disabled People. In particular, Commitments 18.1 and 18.4 (Pillar 4: Health and Wellbeing) points to the need for early, comprehensive support for disabled children and families through an integrated, child- and family-centred early-years structure – of which assessment is only one component²².

Recommendation 1 – Head 6: make guidelines transparent, consulted upon, and subject to oversight

The Committee should recommend that Head 6 be strengthened to require that statutory guidelines:

- are published in full, alongside an accessible plain-language version for families;
- set minimum competency standards for Assessment Officers and any commissioned assessors (including training on intellectual disability, communication/cognitive processing needs, and UNCRPD-consistent disability determination), so “appropriate experience/expertise” is not left to local variation,
- are developed through a mandatory consultation process with disabled persons' organisations and family networks, reflecting the participation obligations the State has recognised in its UNCRPD implementation under Article 4(3)²³
- require consultation not only with DPOs and families, but also with relevant advocacy organisations and professional bodies for the clinical professionals involved, before issuing or materially revising guidelines, and;

²² Department for Children, Disability and Equality (3rd September 2025), National Human Rights Strategy for Disabled People 2025–2030, pg.39

²³ [United Nations \(13th December 2006\). Convention on the Rights of Persons with Disabilities – Article 4. General obligations](#)

- state explicitly that guidelines must be UNCRPD-consistent and informed by clinical best practice and applicable standards (and cannot be used to narrow eligibility or procedural safeguards through guidance or regulations).

This is particularly important because the Scheme indicates the guidelines will interpret legal definitions (including “disability”), emphasise a “high threshold,” and include a structured checklist approach. Because these will shape disability determinations and thresholds in practice, they will directly influence whether children access the wider pathway of supports and inclusive education; not just whether the assessment process moves faster.

This will also support delivery of Commitment 18.4 by ensuring guidance that shapes access to early supports is transparent, consistent and developed with disabled children and their families.

Inclusion Ireland recommends that the State move toward a definition of disability that reflects the UNCRPD’s rights-based approach, recognising disability as arising from the interaction between impairment and barriers²⁴, so that AON eligibility and guidance are grounded in a modern, human-rights and neuro-affirming framework.

Recommendation 2 – Head 6: protect against “checklist gatekeeping” in disability determination

The Committee should recommend that Head 6 guidelines (and any checklist tools) be explicitly constrained so that:

- checklists and examples are decision-support tools, not a substitute for individualised consideration; and
- the process must be capable of recognising disability where needs are substantial but present in less standardised ways (including for children with intellectual disabilities and other neurotypes, and children with additional communication/cognitive processing needs).

This matters because the Scheme lists checklist elements such as “significantly disordered cognitive processes” and “significant difficulty in communication/learning/mobility”.

²⁴ [Ibid, Article 1 – Purpose](#)

Recommendation 3 – Head 6: “non-binding” guidance must not mean “unaccountable”

The Scheme states guidance will be non-binding, reflecting statutory independence of assessment officers. In our view, the Committee should recommend that, even if non-binding, guidelines must still carry accountability through:

- a duty on the HSE to report publicly on implementation (e.g., compliance with key procedural steps and timelines), and
- a requirement that deviations from key procedural elements are recorded and reasoned in the file, to support fair procedures and effective complaints.

These measures support independence while preventing inconsistent local practices.

Recommendation 4 – Head 5 and Head 6: define “deemed withdrawn” narrowly and build in a minimum statutory process

The Committee should recommend that an application may be treated as “deemed withdrawn” only where:

- **Strict criteria:** the HSE has made reasonable, accessible contact attempts and non-engagement is not due to disability-related barriers, inaccessible communication, or service/system failures.
- **Due process:** the HSE issues written accessible notice of intent to close, allows a reasonable chance to re-engage, and – if closed – provides written reasons plus clear complaints/review information.
- **Reopening:** the Act and accompanying regulations provide a straightforward route to reopen the application (without penalty) once the family re-engages or barriers are resolved.

A “deemed withdrawn” closure power risks cutting families off from the support pathway altogether unless it is tightly defined and procedurally safe, particularly given the information and navigation burdens families already face.

Recommendation 5 – Head 7: transitional safeguards for families already waiting

Because Head 7 applies the amendments to applications received where the assessment process has not commenced, the Committee should recommend an explicit requirement that affected families receive:

- a clear written explanation of what changes apply and what does not change, and
- reassurance that any new closure powers or guideline interpretation will not be used to disadvantage families who have been waiting due to system delays.

Recommendation 6 – clarity for families on education needs vs education services

There is a real risk of confusion for families and supporters. The Scheme’s amended definition of “assessment” references identifying “health and education needs . . . and . . . health services or education services . . . required.”²⁵

Yet the Government FAQ document also states that while AON can identify education needs, “identifying the education services . . . is not part of the process.”²⁶

The Committee should recommend that Head 6 guidelines and family-facing materials clearly explain:

- what is included in education needs identification in practice,
- what is outside the AON process, and
- how families access education supports through education pathways (so AON does not become an unnecessary gatekeeper).

Conclusion: AON Reform must Strengthen Trust, not Shift Burdens

Families and supporters want therapies and practical support, and they need a system that is clear, transparent and fair. Inclusion Ireland has highlighted through our wider UNCRPD work that Ireland provides a statutory route to assessment without guaranteeing the therapies and supports identified, leaving families in limbo²⁷.

For children with intellectual disabilities, reform must therefore do two things at once: improve timeliness and hardwire safeguards so that guideline interpretation, checklists and closure powers do not become new barriers to access.

Inclusion Ireland believes this Bill may improve timeliness, but it must not become the limit of ambition. The Government’s pledge to reform the Disability Act²⁸ should be bolder and broader than AON reform. It should set a clear direction for a joined-up pathway from early years to young adulthood, where assessment reliably leads to timely supports and inclusion.

²⁵ Department of Children, Disability and Equality (12th February 2026), General Scheme of Disability (Amendment) Bill 2025, pg.5

²⁶ [Department of Children, Disability and Equality \(12th February 2026\), Frequently Asked Questions: Information on Assessment of Need and Planned Changes to the Process, pg.5](#)

²⁷ [Inclusion Ireland \(27th June 2025\), UNCRPD List of Issues – Rights of People with Intellectual Disabilities in Ireland, pg.3](#)

²⁸ [Department of the Taoiseach \(23rd January 2025\), Programme for Government – Securing Ireland’s Future, pg.92](#)