F.U.S.S.

Families Unite for Services & Support

Cover Letter

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We are making this submission on behalf of the members of our organisation – FUSS Ireland. Fuss stands for ‘families unite for services and support’, it is an organisation focused on supporting families with children and young people who are currently navigating the complex system in Ireland. We campaign on everything related to the life of children with disabilities in Ireland in 2026 and we are willing to participate in a public session at a committee meeting.

F.U.S.S Ireland:

For decades, Ireland's services for children with disabilities have relied on an outdated medical model, violating obligations under the UN Convention on the Rights of the Child and the UN Convention on the Rights of Persons with Disabilities. Children's voices have been systematically ignored, leading to reactive and piecemeal policies, growing service gaps, and highly fragmented support systems. This perpetuates unequal resource allocation and fails to empower families, worsening poverty and isolation. Fuss demands: Every child and family, regardless of disability, deserves timely access to a rights-based system that uses rigorous evidence and data to deliver truly needs-based and child-centred services.

Our submission: Another Patch over a broken system

1. In 2009 the government announced that Education for Persons with Special Educational Needs Act (EPSEN) would not be implemented 'in light of financial circumstances' (the financial crash).[1] The failure to enact critical parts of EPSEN is highly relevant to the wider issues and case law arising from part 2 of the Disability Act.[2] The system of needs assessment which has failed to provide for the rights arising from the assessment has been described as a 'missed opportunity'.[3]

Clear lack of consensus on the role of parent legislation

2. On the 19th Of February Hildegarde Naughton stood up in the Dail and outlined changes being made to the Assessment of Need procedure, which she said included "Development of statutory guidelines to better support HSE assessment officers." It is first important to point out that statutory guidelines already exist and have done since 2007.[4] This amendment claims that these were focused on 'desired' standards and these new guidelines will be 'purely practical'. This distinction is not only contrived but fundamentally illogical: if the existing statutory guidelines (already in place for over 15 years) were merely aspirational, why impose a new statutory duty to produce yet more non-binding documents? What purpose is there in legislating a requirement to create a policy without the force of law, when the HSE could simply issue internal guidance, as it has done repeatedly? This move introduces deliberate ambiguity, shielding the HSE from accountability under the pretence of reform while undermining the clear entitlements in Part 2 of the Disability Act.

3. It is important to point out that these proposed guidelines will remain

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[1] 'Towards 2016 - National Disability Strategy - April 2009'

[2] CTM V HSE [2022] IEHC 131 para 56

[3] Jurgen De Wispelaere and Judy Walsh, 'Disability Rights in Ireland: Chronicle of a Missed Opportunity' (2007) 22 Irish Political Studies 517.

[4] 'Standards for the Assessment of Need' HIQA (2007)

precisely that; non legally binding guidelines. While primary legislation can mandate their creation, the guidelines themselves cannot carry legal enforceability, as this would violate the core constitutional doctrine prohibiting the Minister from sub-delegating the legislative powers vested in her by the Oireachtas. [5] Such delegation would render the guidelines ultra vires, creating deliberate legal ambiguity rather than clarity, and leaving families vulnerable to HSE interpretations that sidestep judicial scrutiny. We contend that this wording has been deliberately crafted to obfuscate the boundaries of the HSE's remit, fostering ambiguity that favours administrative expediency over legal clarity. Specifically, the clause directing guidelines toward "The interpretation of legal definitions in the Principal Act, including the definition of 'disability' and the 'application of those definitions in the context of an assessment" invites misinterpretation that HSE interpretations carry binding weight, despite disclaimers to the contrary.

4. Entrusting an executive agency with a history of rights violations[6] to shape guidance on the Act's foundational term, 'disability', undermines the parent legislation's intent and judicial interpretations, perpetuating systemic failures. If parents now suspect an error in their child's Assessment of Need, their direct pathway to judicial redress will be obstructed by further cumbersome internal complaints processes which have already been deemed ineffective by courts, The Irish Human Rights and Equality Commission and Ombudsman for Children's Office.[7] How can we, as parents, possibly trust an organization repeatedly censured in judicial rulings and official reports for systematically undermining children's

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[5] Article 15.2.1 Bunreacht Na hÉireann

[6] Andrew McKeown 'Court of Appeal Finds That HSE Procedure Imposed Impermissible Barriers on Disability Assessments' (2023) I.L.T 41(20) 281

[7] Irish Human Rights and Equality Commission, 'Ireland and the Rights of the Child: Submission to the Committee on the Rights of the Child on Ireland's Combined Fifth and Sixth Periodic Reports'; 'Unmet Needs A Report by the Ombudsman for Children's Office on the Challenges Faced by Children in Ireland Who Require an Assessment of Their Needs (2020)' 'CTM v HSE [2022] IEHC 131 para 148'

rights in this domain, with authoring “statutory guidelines” that purport to interpret and apply foundational legal terms like ‘disability’? This move predictably amplifies the very ambiguity that has long shielded administrative failures, prioritizing expediency over enforceable rights and judicial clarity.

5. FUSS is firmly of the view that this change will again force parents to traipse back to court and only kick the can down the road for the comprehensive reform we all know is urgently required. The only way that this amendment can result in “faster and more efficient” assessments is by creating sufficient ambiguity around who can and cannot receive a diagnostic report through part 2 of The Disability Act. We must refrain from dressing up this issue as something that it isn’t, the provisions of part 2 of the Disability Act are extremely clear. What is also clear is that we, as a result of the failure to fully operationalise Epsen and in response to the catastrophic failure of Progressing Disabilities, have created a tidal wave of need that we are ill equipped to deal with. This amendment will do nothing for children apart from ensure that, as ever, those children with families who have access to legal advice can access the rights they are entitled to up to a point, but those that don’t will continue to be left behind. If we want to do right by children, we must stop using children with disabilities as political cannon fodder and approach this issue with the rights of the child as the central focus, rather than the neoliberal corner cutting measures of the past.

Autism Protocol

6. *The government statement claims - “Furthermore, the Autism Assessment and Intervention Protocol, launching in February 2026, will provide parents with a faster route of getting an autism diagnosis for their child than the AON route.”* This assertion lacks substantiation and contradicts prior HSE evaluations, such as the 2017 review on supports provided to autistic persons in Ireland[8] which stated there was an unclear picture of the robustness of tiered assessments. [9] In 2019 just prior to the new SOP roll out the HSE commissioned a report on how they may provide more equitable access to assessments. The resulting report offered the statement that *"There is no evidence to suggest that the tiered approach to assessment suggested by the HSE constitutes any significant risk to service users."* There was no mention or reference to what evidence produced such a perspective and the paper opened with a disclaimer that the report was comprised entirely of the views of the author alone.[10] In recommendations of the 2019 paper, statements such as "reinterpreting the AON as described in the Disability Act", "the level of detail should be drastically reduced" and "it should include a brief probability statement on the likelihood of the person having an impairment/disability" became the starting point of the Autism Protocol. A protocol designed to ignore not only the law, but also professional standards, as representative bodies lined up to voice their concern that not only did it fail to align with international best practice[11], it also didn't actually achieve its main purpose, with staff reporting going so far as to state that it 'didn't make much difference'.[12]

Retrospective Application under Head 7

7. The inclusion of head 7 ensuring that any application received but not actioned will be dealt with under the amended act only provides further evidence that the intention here is to wipe the slate clean, effectively nullifying existing backlogs without accountability or redress. Claims of streamlining the process are unsubstantiated and implausible, as true

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[8] 'Report of the Review Of The Irish Health Services For Individuals With Autism Spectrum Disorder' (2017) HSE

[9] Elizabeth Mawle and Peter Griffiths, 'Screening for Autism in Pre-School Children in Primary Care: Systematic Review of English Language Tools' (2006) 43 International Journal of Nursing Studies 623.

[10] Malcolm MacLachlan, 'Towards Equitable Access to Quality Services for Children and Young People with Disabilities in Ireland.'

[11] 'Psychological Society Of Ireland Response to Autism Protocol (2024)'

[12] 'Association Of Occupational Therapists Of Ireland: Response to Autism Assessment Protocol (2025)'.

efficiency cannot be achieved without sacrificing children's statutory right to timely assessments. There is zero empirical evidence, whether that be in data from pilots, comparative analyses, or independent audits, which demonstrate how these changes could possibly improve timeframe adherence. Compounding this, none of the legal advice invoked to justify the amendments has been published, exposing a profound lack of transparency that borders on procedural impropriety and erodes democratic legitimacy. In 2022 the HSE revealed in court submissions that they were entirely unaware that the HIQA standards for assessments had been adopted 13 years previously,[13] but parents are supposed to trust that they will not act outside the law this time based on what exactly? This fiasco mirrors the complete absence of evidence which accompanied the catastrophic failure of Progressing Disabilities.[14] Who needs evidence when we can save money right?

Chronic Lack of Engagement

8. Children with Disabilities have a right to be heard under the UNCRC and UNCRPD.[15] To date, there has not been a single consultation with children on the Disability Act. The National Disability Authority Review of Section 2 in 2011 did not engage with children with disabilities.[16] We must stop acting as though children with disabilities are always represented at a table that is made up entirely of adults. We have valuable insights as parents who have navigated the system, staff have valuable insights as the ones tasked with implementing the system, none of this removes the need to engage directly with the children. We do not know what it is like to grow up in Ireland with a disability in 2026, travelling across cities alone in taxis to our ‘appropriate school places’, pitied faces splashed across

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[13] CTM V HSE [2022] IEHC 131, para 94

[14] Noreen O’Leary and Geraldine Moran, ‘Applying Evidence to the Aspiration for Equity in Children’s Disability Services.’ (2025) 28 Advances in Communication & Swallowing 102.

[15] Article 12 UNCRC, Article 7.3 UNCRPD

[16] ‘“Report on the Practice of Assessment of Need under Part 2 of the Disability Act”, National Disability Authority (2011)’

spreadsheets as our loved ones plead for basic care and support. If this legislation is passed, it will be the latest indictment on this government's failure to ensure the rights of children with disabilities are upheld in this country. They will again be silenced by a paternalistic and neoliberal system which claims to be acting in its best interests but has never stopped for just a minute to ask what those even are.

10. Recommendations

1.Establish a Commission on the status of Children with Disabilities in Ireland (with a similarly broad remit to the 1993 commission) so that children's lives are not siloed.

2. Ensure the commission is not made up of representative organisations focused on securing funding for their cause but instead individuals, focused on the realisation of a human rights-based framework for children.

3. Provide a budget for the commission to engage specialist research on areas of relevance to the carrying out of its function. This is particularly crucial given the unique nature of Ireland's child disability services provision.

4. Ensure the creation and implementation of participation structures for children with disabilities with ring fenced funding to ensure resources are available to ensure the views of all children, regardless of impairment, are facilitated and supported.

5. Ensure the commission finalises its report and recommendations before the next election, establishing clear, time-bound implementation mechanisms with measurable outcomes. This positions the report as a definitive electoral benchmark, holding political parties accountable and ensuring the issue is given the cross party attention it requires.

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