F.U.S.S.

Families Unite for Services & Support

Parents' experiences prior to the rollout of the *Progressing Disabilities* model of service highlighted familiar and concerning themes centred around a lack of child-centred practice, system complexity, and an "us vs. them" mentality that created unnecessary burdens for families already in high-stress situations.[1]

The views presented in this document have been shaped by engagement with the foundational research that purportedly informed the model's creation, as well as by ongoing experiences of participation both within and outside the formal structures for engagement.

Since FUSS was founded in 2022, our core purpose has been to advocate for a shift toward a human rights–focused framework grounded in clear data and evidence.

<u>Key issues:</u>

- Lack of evidence to support the model itself [2]

- Lack of ongoing evaluation and innovation in keeping with evolving understanding of capacity has resulted in policies being still at the development stage despite being based on singular research papers that are now outdated[3]

- No mapping of areas' unique complexities in relation to service providers has created further area disparity. As an example: In an area in Cork where a service provider is co-located with several special schools, many parents chose to stay with the same provider believing they would receive the same level of service at least. This has created a situation where absolutely no 'weight' has been given to caseloads despite them being vastly different. The amount of time 5 children with rare diagnosis who

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[1] Ryan C, Quinlan E. Whoever shouts the loudest: Listening to parents of children with disabilities. J Appl Res Intellect Disabil. 2018;31(Suppl. 2):203–214

[2] OLeary, N. Moran, G. (2024) Applying Evidence to the Aspiration for Equity in Children's Disability Services

[3] Autism Protocol: Maclachlan, M. (2016) Report of the Review of the Irish health service for individuals with autism spectrum disorder

require ongoing postural support and physio is not equivalent to the amount of time that 5 children with sensory support needs will require.

- No international comparative model on the prioritisation methods of interdisciplinary caseloads [4]

- Culture of blame and deflection

- Dilution of clinical competency and the erosion of professional and ethical standards[5]

- The ‘return’ of therapists to schools. This was done on the back of public pressure, which we participated in and which we now regret. We believe that changing your view on something following the furnishing of further relevant info is a forgotten skill, one which the government needs to now lead on. The reality is, we could hire every graduate for the next 5 years and we could still not deliver Progressing Disabilities alongside school based therapy. We are pulling staff from CDNT to cover the schools and shuffling the deck chairs on the Titanic. If this can be delivered alongside it then that is fantastic, but where is the data to support it?

- In our opinion the model does not comply with the rights of the child under the UNCRC or UNCRPD

- Failure to consider the role of parents as both facilitators or barriers to their children despite their best intentions

- Accessibility is non-existent both structurally and physically with many CDNTs still working from inaccessible buildings

- Serious lack of engagement with the children themselves at every level of creation and implementation

- The narrative that some areas have successfully rolled out Progressing Disabilities and therefore it can be done, despite no evidence to suggest that this is anything more than an area doing well in spite of and not because of.

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[4] National Disability Authority, Literature review on the prioritisation of referrals in interdisciplinary teams (2024) Prioritisation working group on prioritisation (2023,2024)

[5] AOTI, IASLT, IASW, ISCP and PSI joint statements October 2023

- Gaps in the system are being plugged with the creation of endless pathways for specialist services (which are arguably not specialist at all – continence care for example was never considered a speciality prior to reconfiguration) and the DRESS system alongside pathways for individual diagnosis and rare diagnostics. This has made a complex system downright impenetrable.

Recommendations

1) The Medical Council's guide to professional conduct and ethics protects not only the public, but the professional standards of registered medical practitioners in Ireland. Society as a whole benefits when professional standards are maintained and consistently built upon. Throughout the course of the role out of Progressing Disabilities, every representative organisation (see PSI/AOTI/ISALT) has spoken out about the denigration of previous minimum standards. This is not about being negative towards staff, this is about empowering them and recognising that they have a specialist skillset which is worthy of protection.

Coru maintains the standards of the professionals, but who maintains the standards of the service providers? We have a system at present which regulates the provision of lip filler more than the provision of disability services for children.

2) Creation of a specific role for research and data collection in relation to children’s disability services with a minimum level of three staff members. Create a clear framework for monitoring and evaluating the effectiveness of same. It is vital that they are people who understand what data and research is relevant to the area. Progressing Disabilities is an obscenely complex policy that sits within a system that is further complex, we need more people to admit they have absolutely no idea how any of it works.

3) We need to ensure that the voice of the child is included at all levels of decision making, being a parent does not equal lived experience and priorities for families do not always align with priorities that the child themselves have. We must recognise and encourage the evolving capacities of children with disabilities while ensuring that it is understood that every single person communicates, and a lack of verbal speech does not mean that a child cannot express choice. Proximity to a disabled person must not be treated as lived experience of disability.

4) Audit policy for adherence to HIQA standards (which are currently not

being followed) and move away from token engagement[6]

5) Utilise independent legal experts focused on making our legislation compliant with international human rights obligations and not, as it currently is, reducing liability exposure to the HSE.

6) Tackle the culture issues by implementing a senior accountability regime similar to that enacted within the banking sector.[7] A statement of responsibilities would allow for ownership of tasks and empower staff by ensuring that their remit was very clearly defined. This would also reduce the administrative burden at a local level in relation to parliamentary questions and media enquiries.

7) Focus on universal accessibility – many parents have disabilities and children of people with disabilities are disproportionately represented in child care cases.

8) Review and amend the Disability Act completely independent of the HSE and NDA. We need this legislation amended to reflect the dynamic nature of disability but without diluting the basic rights it affords children. It is overwhelmingly obvious that it is not working and we need to stop spending obscene amounts of money on 'autism protocols' in an attempt to get around its very clearly defined purpose. If we had spent half the time and effort that was put into the variety of procedures and protocols into action in this area then the state could have saved itself a frightening amount of money. (Please see statement re:Autism Protocol below)

9) Implement a family navigator programme: paid peer support [8]. We have a staffing crisis in the sector and an entirely untapped workforce of carers who are unable to commit to more than 18.5 hours a week. Why are we not bringing both together ?

10) The cycle of policy creation within children's disability services currently involves seeking to ensure that someone is at the table from each discipline. This is not in line with the HIQA recommendations for policy creation and it has resulted in a cycle that is deeply time consuming and harmful to both staff and families alike. Inevitably the policy is created, staff or families express concern that said policy could not be implemented in my area even with the best will in the world. This

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[6] Hiqa, Prioritisation process for the development of national standards and guidance for health and social care services (2020)

[7] Central Bank (Individual Accountability Framework) Act 2023

[8] Burke MM, Cheung WC, Kim J. Understanding the Effectiveness and Feasibility of a Family Navigator Program for Parents of Children With Autism. Intellect Dev Disabil. 2023 Oct

leads to a lack of cohesive application as individual areas create and maintain their own policies. This compounds significant challenges in providing appropriate support and erodes trust with parents who have no idea what policies are in place in their area and no recourse to complain when they are not followed.

11) National complaints department dealing solely with children's disability services which recognises that families have the unique and valuable perspective of navigating a system from start to finish. Complaints are rarely an attempt to cause harm, they usually come from a place of hurt and seeking to avoid the repetition of harm to others.

Note: Please see the statement below detailing our decision to withdraw from the NDA review of Children's Disability Services.

Conclusion

We are not here to tell you we have the answers, nor to tell you we speak for all parents. We don't. We speak only as parents who have navigated the system, we speak as advocates whose interest in this area has led us to attempt to find a different way forward. We are not asking you to go out and ask every parent what they think, though diversity is essential as minorities are sorely under-represented. We are asking for swift action which is informed by evidence and research. We ask that the government take note of the lack of research and data in this area and cease reactive responses without sound foundations. We must stop focusing on parents and staff and start putting the child themselves at the centre

Statement FUSS Ireland on Autism Protocol

Concerns Regarding Autism Pathways Protocol and Consultation Process

Dear X

I am writing to formally document a number of serious concerns regarding the Civil Society Feedback Report and the associated consultation process on the Autism Assessment and Intervention Pathways Protocol presented on March 19th, 2025.

1. Inadequate Consultation and Representation

While the report emphasizes input from civil society, the structure of the session resembled a curated presentation rather than a meaningful consultation. Many participants noted that difficult questions were avoided and time for genuine feedback was limited. The lived experience representation appears tokenistic, with only a few parents involved over several years. This falls short of the principles of co-design and inclusive decision-making, especially for a protocol with nationwide implications.

2. Overreliance on Tiered Assessment Without Safeguards

The tiered approach, while potentially valuable in some contexts, raises concerns about oversimplification of complex cases, especially for children with co-occurring conditions such as intellectual disability or mental health needs. The protocol’s suggestion that "obvious" cases be fast-tracked risks marginalizing those who mask or present atypically, including girls and children from underrepresented communities. The notion that some children do not “appear autistic enough” is deeply problematic.

3. Neuroaffirmative ≠ Not Disabled

We are alarmed by the emerging narrative suggesting that adopting a neuroaffirmative lens may lead clinicians to determine that autistic individuals are not disabled. This interpretation threatens to undermine children’s access to services under the Disability Act 2005 and Assessment of Need. Diagnosis under DSM-5 or ICD-11 does not preclude disability status; to imply otherwise risks eroding protections and entitlements for many.

4. Lack of Legal and Ethical Clarity

The report fails to address how the protocol aligns with statutory obligations. The suggestion that an autism diagnosis may not equate to a “substantial restriction” under the Act, based on perceived functionality, is not only legally questionable but ethically troubling. There is no evidence the protocol has been reviewed for compliance with disability law.

5. Children with Down Syndrome and Other Disabilities Left Out

It is especially concerning that the protocol and consultation have overlooked children with Down syndrome and ID, many of whom experience dual diagnoses and face systemic exclusion from timely assessments and appropriate interventions. Down Syndrome Ireland and Inclusion Ireland's support is crucial in addressing this gap and ensuring these children are not rendered invisible in autism policy development.

In Summary:

We urge a suspension of the protocol's implementation until there is:

- A fully transparent and accessible public consultation process.
- Legal review of the protocol’s implications for disability rights.
- Robust clarification that neuroaffirmative practice must not be used to justify denial of disability status or services.

We look forward to a formal response and a commitment to inclusive, rights-based policymaking.

FUSS Ireland

Statement on FUSS Ireland withdrawal from NDA review (also published on our website and across SM channels)

FUSS Ireland has been calling for a review of the Progressing Disability Model in the delivery of children' s disability services for several years. Therefore, it feels appropriate to explain why we have made the decision not to participate in the current review being carried out by NDA Ireland as outlined in the Roadmap for Progressing Disabilities.

The reason we have decided not to participate is because we believe, upon its conclusion, all we will have is a review that tells us how this service model aligns with a litany of buzzwords based on utterly unreliable data.

After years of studying, researching and engaging in every angle of PDS, it is our firmly held belief that it cannot deliver. We are tired of watching staff be berated for failing to implement a system so flawed that no comparative data exists to support it. We are tired of watching families endure unbearable suffering and heartache at a time when we should be empowering them.

We do not feel that this review, with its current terms of reference which have been altered for the worse, can deliver what is needed. And what is needed is acceptance without blame but a focus on moving forward together.

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FUSS IRELAND

Rachel Martin, Rebecca O’Riordan, Edwina McElhinney and Gavin Owens