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## **Neuro Pride Ireland**

**Opening Statement to the Joint Oireachtas  
Committee on Children, Disability, Equality,  
Integration and Youth  
on the Autism Spectrum Disorder Bill 2017**

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A Cathaoirleach, a Leas-Chathaoirleach and esteemed Members of the Committee, thank you for your invitation to this Committee session to provide Pre-Committee Stage detailed scrutiny of the *Autism Spectrum Disorder Bill 2017*.

Neuro Pride Ireland is a national Disabled Persons Organisation representing neurodivergent people from, or living on, the island of Ireland. We were founded as a cross-neurodivergency organisation in response to community need, as the majority of neurodivergent people have more than one neurodivergent identity; for just one example, up to 80% of Autistic people also have ADHD.

In addition to holding monthly peer support, cultural and social events and an annual festival for our over 1,000 members, we also produce educational materials and actively advocate for neurodivergent people's right to full participation in all aspects of society.

We welcome the Committee's invitation to participate in this discussion today on behalf of the Autistic community we represent.

Before speaking to the *Autism Spectrum Disorder Bill* in detail, we wish to recognise Deputy Canney's dedication to upholding disabled people's rights and making real the vision of lives of quality and equality for all disabled people offered by the UN CRPD, as evinced by his work with the Disability Matters Committee as well as his work as a Teachta Dála. When we spoke with him back in November of 2021, we welcomed his acknowledgement of the importance of removing dehumanising and stigmatising language from this Bill - which uses the word "disorder" in connection to Autistic people more than 50 times in the space of 5 pages - as well as addressing its troubling aspects regarding data collection. As Ireland's only national cross-neurodivergency Disabled Persons' Organisation, we look forward to following through on his offer that day to work with all stakeholders to ensure that this Bill is as robust as rights-based as possible under his stewardship.<sup>1</sup>

An important facet of this and one we wish to raise is the importance of including the views of the least heard members of the Autistic community, such as non-speaking people, those with intellectual disabilities and those from minority communities who often have invaluable insights that should inform any proposed legislation, strategy or intervention impacting on their lives.

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<sup>1</sup> Aligning Disability Services with the UN Convention on the Rights of Persons with Disabilities: Discussion (Resumed), Joint Oireachtas Committee on Disability Matters (4 November 2021), p.18: [https://data.oireachtas.ie/ie/oireachtas/debateRecord/joint\\_committee\\_on\\_disability\\_matters/2021-11-04/debate/mul@/main.pdf](https://data.oireachtas.ie/ie/oireachtas/debateRecord/joint_committee_on_disability_matters/2021-11-04/debate/mul@/main.pdf)

We have been following the work of this Committee, and the work of those of its Members who also serve on the Disability Matters Committee, with interest, and believe we have a shared recognition of the importance that the principles and provisions enshrined in the *UN Convention on the Rights of Persons with Disabilities* inform discussion of all aspects of the Bill. This Bill was originally drafted prior to Ireland's ratification of the UN CRPD and so there are a number of areas in which its provisions fall short of full alignment with the Convention; we propose that a specific amendment stating a commitment to upholding Autistic people's CRPD rights be included to provide a useful reframing as well as to clearly signalling that this legislation is no way intended to create a segregated approach to Autistic people's rights and issues. We therefore suggest that **§3(1)** of 2017's Bill be amended to acknowledge that Autistic people are not just users of services but full and equal citizens by stipulating that a National Strategy focused on Autistic people requires a whole-of-Government approach, and that advancing Autistic people's access to the full range of UN CRPD rights must be an explicit and overarching aim of any such Strategy.

A national UN CRPD Implementation Plan is currently being drafted to succeed the lapsed National Disability Inclusion Strategy; to avoid any unintentional siloing of the Autistic community, we propose that - should the UN CRPD Implementation Strategy be published within current timelines - the Bill be reviewed against that Strategy, to ensure that the Bill aligns with its strategic goals and to include measurable outcome targets in advancing this Strategy where appropriate.

While we acknowledge that many of the concerns we wish to raise may have already been noted by the stakeholders Deputy Canney has worked with prior to this Committee session, and he may have already drafted amendments which address these issues, we can only comment on the Bill as available to us and so we apologise in advance for any repetition of points already raised elsewhere.

As mentioned, we know that the language and Medical Model approach of the Bill have likely undergone a thorough review. We also trust that the language in **§3(d)** directing that "*the wishes of the [individual]... be taken into account in so far as is possible*" has been corrected to direct that the will and preferences of the individual must be central to any decision affecting them, and that the *Interpretation* section has been updated to reflect the transition of Disability Services from the HSE to the Dept. of Children, Equality, Disability, Integration and Youth in the revised Bill, and so won't speak to those details here but instead provide a brief overview of the aspects of the Bill we wish to highlight or to seek clarification on.

## Definition of persons falling within the scope of this Bill

- In **§1**, the 2017 Bill refers to a number of conditions who are now better understood as frequently co-occurring with, but separate to, being Autistic as well as including outdated and no longer used diagnostic labels, yet makes no acknowledgement that the majority of Autistic people are Neurodivergent in more than one way; a fact which greatly impacts their experiences, and the supports which would best allow them to flourish. The DSM-5 no longer includes Rett's Syndrome or Fragile X under autism, and Asperger's Syndrome has not been a recognised diagnosis since 2013.<sup>2</sup> Rett's syndrome and Fragile X are completely separate classifications in the ICD-11 (code LD90.4 and Code LD55 , respectively). It is important that this is updated in the revised Bill.

## Consultative duty of the Minister

- This Bill was drafted and progressed before Ireland's ratification of the UN CRPD in 2018, and therefore hasn't been through any consultation process required to align with the treaty's commitments. We know that the Bill's sponsor, Deputy Canney, has served as an active and dedicated Member of the Joint Oireachtas Committee on Disability Matters and hope that the Deputy already intends to explicitly expand the consultative obligations outlined under **§2(1)** of this Bill, not waivable at the Minister's discretion, to include consultation with Autistic people. Any such consultation must include non-speaking Autistic people, primary users of Augmentative and Alternative Communication (AAC) and those who are also otherwise disabled, through as broad a platform of their representative organisations as is practicable in-line with Article 4(3) of the UN CRPD.

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<sup>2</sup> 'Autism Spectrum Disorder Versus Autism Spectrum Disorders: Terminology, Concepts, and Clinical Practice', Lindsay M. Oberman & Walter E. Kaufmann, [Front Psychiatry](https://doi.org/10.3389/fpsy.2020.00484). 2020; 11: 484. (May 2020).DOI: [10.3389/fpsy.2020.00484](https://doi.org/10.3389/fpsy.2020.00484)

## Provision for annual assessment

§3(b) introduces a provision for repeated assessments of Autistic people, at least annually for children and at unspecified frequency for adults “to establish the level of ability, disability and social awareness.” Beyond its outdated and problematic language, it is unclear from the text of this provision whether the assessment is intended to be a diagnostic assessment, a full Assessment of Need (AoN), or assessment of another nature (for example, to help identify the most appropriate services and supports for an individual across their lifespan).

- As is now understood, autism is a life-long neurodevelopmental difference meaning repeated diagnostic reassessment would have no value while placing enormous stress on both the individual and their family, and on State services which already are unable to meet the level of diagnostic need. A formal AoN process is also not practicable or desirable on a yearly basis, with waiting lists across the country already backed up for more than a decade.
- We would welcome clarity on this provision and the assessment requirement it introduces, particularly in view of the far-reaching changes made through the introduction of Children's Disability Network Teams (CDNTs) and proposed Progressing Disability Services framework. We also would like as much information as possible as to whether any such assessment would include mental health assessment and support, which is currently gravely lacking. Despite having much higher risk of depression and suicide than their peers, many Autistic children in Ireland are denied access to CAMHS due to their autism diagnosis.
- We are also concerned with the requirement for a multi-disciplinary assessment in all cases. While we believe that families should be able to access multi-disciplinary support, outside of a diagnostic process often they are best placed to identify the most appropriate support for their individual needs at a given time. A finite list of professionals may also be problematic, depending on what this assessment is for, especially in its inclusion of behavioural therapists in a manner which indicates this is interchangeable with other professional qualifications. The recent Joint Oireachtas Committee on Disability Matters Report, *Aligning Disability Services with the UN CRPD*, found that there is reason to believe that behavioural therapist intervention practices do not align with the CRPD.<sup>3</sup>

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<sup>3</sup> ‘Aligning Disability Services with the UN CRPD’, Joint Oireachtas Committee on Disability Matters (published: 23 Feb 2023), ‘Free and informed consent’, Item 60, p.24. ([Report pdf](#))

## Capacity in relation to expression of will and preference

This Bill was drafted when the Victorian *Lunacy Act* of 1871 still provided legislative underpinning to issues of disputed capacity in decision-making in Ireland. With the introduction of the *Assisted Decision-Making Capacity Act*, we moved towards a more rights-based and informed understanding that ‘capacity’ isn’t to be viewed as a binary state an individual either does or doesn’t have, but a dynamic framework within which the State, through its agents and those working directly with individuals, have a duty to provide all possible supports to empower individual decision-making on a case-by-case basis.

We therefore believe it is of crucial importance that specific focus is given to ensuring that **§3(b)(vii)(II)** of this Bill reflects the more mature understanding of capacity we have gained in the intervening years, and doesn’t inadvertently undermine the provisions of the *Assisted Decision-Making Capacity Act (ADM)* and its attendant mechanisms, such as the Decision Support Service.

- We are concerned that the language used around capacity does not reflect the provisions of the ADM and is not compliant with the rights enshrined in the UN CRPD, including and notably those guaranteed under Article 12. It is important that this Bill be updated to reflect the requirements for appointing a Decision-Making support person since the enactment of the ADM, we also wish to raise that there is significant evidence to suggest that Autistic people - particularly non- or partially speaking Autistic people, those with various forms of apraxia and Autistic people with Intellectual Disabilities - are particularly disadvantaged by functional tests of capacity as used under the ADM. Such inherent inequality of outcome is a reason why the use of functional tests of capacity is not deemed compliant with the CRPD. We believe that discussion of capacity within this Bill could be valuably used to highlight how decision-making capacity of Autistic people is routinely underestimated, and to place a specific duty to ensure each Autistic person’s communication and decision-making is supported insofar as possible in expressing their individual will and preferences.
- We believe it is essential that any provision relating to the expression of preference or consent to services restate a commitment to ensuring all Autistic people have access to a full range of communication support including robust AAC options.

## Provision for data collection

- We have particular concerns about provision **§3(j)** of the Bill which deals with the collection of data from service providers. As much as the original Bill predates Ireland's ratification of the UN CRPD, it also predates Ireland's adoption of GDPR and enactment of the Data Protection Act 2018. We are unclear on the scope and oversight of this data collection, its intended purpose, and how compliance with all relevant data protection laws and regulations will be ensured.
- If its purpose is for population study and to measure the number of Autistic people in the State, this is better done via Census data through existing mechanisms, as previously advised by Adam Harris of AsIAM. Although the issue of Autistic people not being captured in Census - previously raised by AsIAM, ourselves and other DPOs - had not been resolved at the time of the most recent Census, it remains most appropriate avenue for population-based data collection and we reiterate our offer to work with the Central Statistics Office to address this alongside our fellow DPOs.
- If the purpose of this collection of data is to measure capacity requirements of supports and services we, again, do not believe this is an appropriate avenue for this aim. Any data collected through services in this way can only reflect those already engaged with the existing services, not give a robust picture of existing unmet need for services. By definition, data thus collected will reflect existing gender and ethnic inequalities in identification and access to services and overlooks that the majority of Autistic people in Ireland lack official diagnosis, both of which are exacerbated by Ireland still having no public pathway to adult diagnosis. These factors mean that those people currently engaged with services are not an accurate representation of the entire Autistic population - there is a risk that trying to use existing service user data in a predictive manner may very well further entrench existing biases and inequalities.
- Collection of information from services also poses an increased data risk; access to services may indicate the presence of a specific formal or 'medical' diagnosis and, particularly with some specialist services and/or with individuals with uncommon co-occurring conditions, could potentially result in the transfer of sensitive, special category or personally identifiable data, even if anonymised.

- There is a legitimate and genuine wariness about data collection and creation of a de facto 'Autistic Register' amongst the Autistic community, our families and our supporters necessitating transparency around how and why data relating to us and our families is collected by State bodies, including transparency about who may have access to it and how it is to be used. This distrust is not unfounded, as shown by the recent Autism Dossiers controversy and HSE data breaches.
- We strongly urge that an explicit provision be incorporated into this Bill to require that a Data Protection Impact Assessment be conducted prior to the collection of any data or creation of a database, and that this impact assessment specifically address whether any data so collected could potentially fall within the scope of special categories of data outlined under GDPR, alongside a report with recommendations on risk mitigation.

### **Additional observations**

- To ensure embedding of UN CRPD principles across the Bill, we believe that **§5(2)** and **§8(1)**, and any additional or amended provisions as appropriate, should make specific reference and confer an explicit duty to close consultation with DPOs, statutory bodies such as IHREC and other relevant stakeholders. In the case of **§8(1)**, it is essential that any awareness campaigns developed under the Strategy are co-developed with Autistic people and their representative organisations themselves and, where possible, delivered in partnership with them. We further suggest that staff in public services and all bodies subject to Public Sector Duty should be named in **§8(2)** in order to enhance the inclusion of Autistic people in all aspects of public, cultural and civic life.

Once again we wish to thank the Committee Members and Dep. Canney for this opportunity to represent the interests and concerns of our membership, and look forward to engaging with you on this topic and answering any questions you may have.