



**Adam Harris (Founder-CEO of AsIAM, Ireland’s National Autism Charity) – Opening Statement to Joint Oireachtas Committee on Disability Matters – “Aligning Disability Services with the UNCRPD – autism and intellectual disability”**

Chairperson, Deputies and Senators:

May I begin by thanking you for the opportunity to present to you today on this important topic. My thanks also to the Clerk and staff of the committee for all their assistance in advance of this meeting.

AsIAM is Ireland’s National Autism Charity. We are an organisation which takes a rights-based, accessibility approach to autism acceptance and inclusion. Approximately half of our team are neurodiverse and we undertake a broad range of work in supporting autistic people, advocating for the rights of our community and engaging with broader Irish society on the steps which can be taken to make communities more inclusive. We welcome the opportunity to discuss autism services in the context of the United Nations Convention on the Rights of Persons with Disabilities. At the outset of the discussion it might be worth noting some fundamental, structural flaws to autistic people and our families in accessing services which are in full alignment with Ireland’s obligations under the convention. The Convention itself deals with rights and rights holders. Recognising that disabled people have a right to access the support they need to participate in a society which too often presents barriers to our community. However, Irish systems and services continue to operate on a paternalistic grace and favour, charitable model in which the systems often dictate the supports that people are able to access and that autistic people and their families have even less recourse when these systems and services don’t respond to their needs or indeed fail. Not only this. Whilst it is deeply regrettable that Ireland was the last country in the European Union to ratify the UN Convention, it remains that we do not have a clear timetable for the ratification of the Optional Protocol. A convention with no mechanism for complaint and resolution for people with disabilities does little to help autistic people whose services are not delivered on a rights-based model. Finally, it is to be noted that our entire approach to disability in this country continue to be rooted in the Medical Model, and not the Social Model or Human Rights Model set out by the Convention, and is often driven and controlled by the interests of large service providers, or the HSE’s capacity to deliver services, and not by the needs of autistic people and their families on the ground. “Nothing about us without us” is far from the reality when it comes to the design and delivery of autism services which often are not designed with autistic people, least of all autistic individuals ourselves, in mind.

Stepping away from those structural realities, what is it like in Ireland to access, or attempt to access, disability services as an autistic person or family? In AsIAM, we deal with thousands of queries from the community every year, covering a broad range of topics from access to

diagnosis to therapeutic supports and everything in between. The one word which comes to mind across all these categories and indeed across the entire life course is fight. Autistic people and our families have to fight, often until the point of fatigue, from the word go to access the most basic supports – in some instances these are supports which are specific to autistic people and provided through disability services but sadly even mainstream health services, particularly our mental health services, do not afford parity of access to care for autistic people, despite 8 in 10 of our community experiencing mental health conditions during the course of our lives and autistic people, without an intellectual disability, being 9 times more likely to die by suicide. This is far from a rights-based approach.

We documented some of these barriers in our recent report “Every Child Counts” which looked at the experience of autistic children in accessing HSE services. The realities are bleak:

42% of families had to wait over 2 years to access diagnosis

79% were not in receipt of any support from either the Early Intervention or School Aged Teams

65% were dissatisfied with disability services

Just 7% were in receipt of any respite support

The consequences of these barriers are real, and can often be devastating for autistic people and their families. It means children experiencing unmet needs. It means families losing the opportunity to participate fully in the community and it also often leads to poverty and to social exclusion. A study from NUI Galway showing that families of children on the autism spectrum experiencing additional costs of €28,000 per year due to being forced to access private services, leave work or go part-time due to a lack of appropriate supports. This chimes in with the experiences of many disabled people and their families, who often experience additional living costs of between €10,000 and €14,000 per year.

The situation does not improve when we look at how supports are provided, or usually do not exist, for autistic adults. Adults within our community who did not have their needs recognised or met as a child can only access an autism diagnosis privately, usually at a cost of nearly €1,000. Autistic adults attending day services are often attending services designed not for themselves or for autistic people but for those with intellectual disabilities. The long delays in seeing the commencement of the Assisted Decision Making Act have seen many autistic people continue to have their rights undermined by the so-called Lunacy Act of 1871. Autistic people living at home or living independently in the community can often access no formal support structures and all-too-often isolation, poverty, social exclusion, unemployment and mental health crises are a norm for adults within our community.

Just as it is important to recognise that disability rights aren't about services, we should also recognise that services are about more than resources. Earlier this year our organisation argued for the need for a cultural reset in how the HSE and Department of Health interact with autistic people and our families. The crisis of trust generated by the recent RTE Investigates programme, coupled with the often adversarial, if not hostile, experience autistic people and families have whilst engaging with services and more broadly, as a result of recent abuse scandals such as Aras Attracta and Ard Greine, highlights the need for our services to become more person-centred and rights based. Put simply we need the system to

collaborate, not gatekeep or dictate, and to gain a greater empathy and understanding of the experiences of our community.

In conclusion? What steps would we recommend to the committee to bring about a full alignment between autism services and the UNCRPD. We would advise the following:

- We welcome the Government's recent commitment to return to legislation in 12 month's time concerning the National Autism Strategy and Minister Rabbitte's commitment to an Autism Innovation Strategy. There is a clear political consensus for this Strategy which will serve as an important recognition by the State of the specific needs of autistic people. We need no obstacle to stand in its way
- It is vitally important that the HSE progress public pathways of support for autistic adults to access both diagnosis and support but also for autistic people of all ages to be able to access mental health services in a timely manner
- Learning from the experiences of the NHS, an obligatory training programme in autism should be rolled out to all staff working in disability and health services. It remains that many staff do not have the training they need to meaningfully meet the needs of autistic service users
- Urgently bring above a revision of the approach to autism and disability within the HSE to move us towards a rights-based model.
- Fully fund the findings of the Disability Capacity Review, which identified that an extra €350 million is required to fully meet the need for disability services across Ireland. Despite the additional funding for disability services set out in Budget, there remains €230 million shortfall after Budget 2022
- COVID-19 highlighted for all to see the shortfalls in our disability services. Never again can services such as Occupational Therapy (OT) or Speech and Language Therapy (SLT) be treated as optional extras during a moment of major crisis where autistic people lost routine, predictability and vital support overnight. We must now use it as an opportunity to questions why things have always been done a certain way? To ask is there a better way and critically to listen to the lived experience of autistic people and our families.

I thank the Committee for your time and I look forward to your questions