

Adam Harris (CEO – AsIAM, Ireland’s National Autism Strategy) – Opening Statement to the Joint Oireachtas Committee on Children, Equality, Disability, Integration and Youth on the proposed “Autism Spectrum Disorder Bill” – 3rd October 2023

Chairperson, Deputies, Senator

I would like to begin by thanking the Committee for its invitation to speak to the proposed legislation. At the outset, I would like to pay tribute to the work of Deputy Canney and the Regional Group in their work championing and progressing much needed legislation in this area, as the then Senator Reilly did in the last Oireachtas.

My name is Adam Harris and I am the CEO of AsIAM and am also an Autistic person. By way of introduction, AsIAM is Ireland’s National Autism Charity. Our vision is a society in which every Autistic person is accepted “as they are” – equal, valued and respected. We are an Autistic-led organisation and our purpose is to advocate for an inclusive society for autistic people that is accessible, accepting and affirming. We work to support the autistic community and our families to fully engage in Irish life and build the capacity of society to facilitate true inclusion. This work includes the operation of an Autism Information Line, the provision of group-based supports to Autistic children, families and adults and training and accreditation programmes across Irish society, including in schools, workplaces and local communities.

As members may be aware, Autism is a lifelong, developmental difference which relates to how a person communicates and interacts with others, and how we experience the world around them. Autism is a spectrum, and this means no two Autistic people are the same and the levels of support an individual may require in day-to-day life can vary greatly. This different way of thinking means that Autistic people are neurodivergent, and this different way of thinking means Autistic people can face significant accessibility barriers in Irish society which can be disabling. It can also mean each individual Autistic person has strengths and abilities which need to be emphasised and harnessed to ensure not just that person’s full participation in society but their contribution also. Many members will no doubt know Autistic people, be it in your family or friends, it is important to recognise that at least 3.38% of children in school in Ireland today have an Autism diagnosis and we can assume that this prevalence, diagnosed and undiagnosed, exists across Irish society. It is important to realise therefore that we are talking about an extremely diverse and individual cohort of people.

Whilst every Autistic person may be different, the barriers faced by our community are all too familiar to many of us. Autistic people face barriers in Irish society which others do not even see and in turn do not enjoy the same chance in almost every aspect of Irish life and society.

Indeed, our annual Same Chance Report provides something of a “state of the movement” insight into these barriers. This year, the report documented the experience of over 900 Autistic people and family members who reported both specific barriers linked to being Autistic in Ireland and heightened challenges and adversity on issues which our country is contending with as a whole. These statistics included:

- + 90% do not believe the public understand enough about Autism
- + 91% had experienced barriers in gaining acceptance and forming friendships
- + Just 12% believed that the portrayal of Autistic people in the media was accurate and respectful

- + 83% believe they had to mask or change who they are to have the same chance to participate in day-to-day activities
- + 76% believed Autistic people were treated differently in a negative / very negative way in society
- + 52% do not generally disclose their diagnosis to others.
- + 57% do not feel supported by their broader family unit

If these pervasive barriers were not enough, a lack of sufficient, timely support is a near universal experience for our community. “No, we can’t support you”, “Unfortunately there is a waiting list for that”, “I am not the right person to talk to” are a chorus of rejections which individuals and families contend with, right across the lifecycle. These barriers were brought to life by those contributing to our Same Chance Report:

“Well they are on the books but services are lacking due to staff shortages. Only half the quota of staff are available and there are over 400 children on the books and another 271 waiting. Unfortunately you have to shout loudest to be heard, puts a terrible strain on families”

“We receive little to no support, and if we didn’t chase or follow up with them, we’d get nothing. Maybe a couple of hours of support in the last 12 months”

“No really receiving much. I was very hopeful of the last group for my son but he was lumped in with kids much younger than him. It felt like ‘offer them something’ rather than understanding his needs and giving him something appropriate that work actually help him”

“After 51 month wait - he has had a gross and fine motor assessment and handwriting assessment from CDNT nothing else to date”

These stories are just small anecdotes from one survey in a community which truly is facing a crisis of support across both child and adult services delivered by the key department and agencies of the state.

This is why we passionately believe in the need to legislate for a National Autism Strategy. Such legislation would serve as a recognition of the pervasive and distinct challenges faced by Autistic people and provide a long term, sustained and statutory framework to provide the same chance for our community.

I want to acknowledge the commitment of Minister Rabbitte to the publication of an Autism Innovation Strategy, a process in which our organisation is heavily engaged. We also welcome the recent publication of the Final Report Joint Oireachtas Committee on Autism. The 109 recommendations identified by the Committee provide a roadmap for change however we know that all too often superb strategies and reports have sat on shelves. Indeed, our community has awaited meaningful action and implementation since the first Taskforce Report on Autism in 2001. That is why the critical recommendation of the report is to legislate for such a Strategy and it is this proposal in today's legislation which we see as of critical importance. Since 2012, all parties represented in the Oireachtas, at one stage or another, have indicated their support for such legislation. It is long overdue that that support was given full legal effect to ensure the excellent work which has been done in recent months is not lost due to an election or change in government priorities.

AsIAM is presently running a campaign in which we are asking all Deputies and Senators to indicate their full support for the implementation of the Final Report of the Joint Oireachtas Committee on Autism and for the recommendation on legislation to be implemented in the lifetime of this Oireachtas. We are also asking families across Ireland to write to their local representatives in relation to the campaign and have written to every state agency and department referenced in the recommendations to seek a meeting and ask for a response to their specific recommended actions. It is our intention to publish an annual scorecard on implementation.

In conclusion, our organisation is supportive of the need to legislate for a National Autism Strategy and for the intentions of this bill. Should the bill proceed it is important that it is reviewed to ensure the most up to date language around Autism is used throughout and that the approaches to support described within the bill are neuro-affirmative and rooted in the principles of the UNCRPD. Our organisation will be delighted to assist the Committee and individual members in this work and I look forward to our discussion today.