



IRELAND'S AUTISM CHARITY

Opening Statement – Adam Harris, CEO of AsI Am, Ireland's Autism Charity

Chairperson, Deputies and Senators

Thank you for the invitation to speak to you today on this important topic. My name is Adam Harris, I am Autistic and I am the Founder and CEO of AsI Am, Ireland's Autism Charity. I am joined today by our Senior Policy Officer, Mr Adrian Carroll. Our organisation is celebrating 10 years of activism this month and our vision is an Ireland in which every Autistic person is accepted "as they are" – equal, valued and respected. We are an Autistic-led organisation which places lived experience at the heart of everything we do – both in terms of the supports we provide to our community, the advocacy we conduct on its behalf and our efforts to support communities, organisations and individuals to take steps to address the pervasive but often invisible barriers which decline the, at least, 1 in 27 people in Ireland who are Autistic from enjoying the same chance. We welcome participating in today's discussion during World Autism Month which provides an important opportunity for our organisation to centre the voice of our community and highlight the human rights issues which confront our community on every day, of every month, of every year. It is also a pleasure to participate in this discussion on the importance of self-advocacy and the role of DPOs as a proud member of the DPO Network.

Ensuring access and dignity to public services is of critical importance to our community, it is also a right which Autistic people are told we already have. That said, the lived experience of our community on the ground tells a very different story. Just last week, AsI Am published our annual Same Chance Report which documents the experiences of some 1700 Autistic people in Ireland, across the life cycle. The report also captures public attitudes to Autism through a poll of a representative sample of 1,000 Irish adults. The data presented captures clearly that in interacting with public services, across government, Autistic people face barriers not experienced by others. Key findings included:

- 53% of those represented had to access their assessment privately
- 60% were on waiting lists to access a range of basic supports
- 71% do not believe, based on their experiences, that our healthcare system is inclusive and accessible of Autistic people
- 66% of those in receipt of social welfare payments said that the current rates were not enough to meet their needs, with 74% incurring additional costs due to being Autistic
- Whilst a majority felt that the education system was not inclusive of Autistic people, 1 in 4 reported not having access to a suitable school place that meets their needs, with 29% reporting that their child had been placed on a reduced timetable without their consent.

Against this backdrop it is not difficult to understand why 90% did not believe they had the same chance as non-Autistic people in Irish society with 73% feeling that there were treated differently in a negative way and 83% feeling that they had to change who they are in order to receive the same chance in day to day activities in Irish society.

Autistic people in Ireland clearly do not enjoy the same chance but what can be done to address this? It is notable that our community identified a lack of access to supports and services and the judgement and attitude of others as the two greatest barriers to inclusion in the community. In many respects these barriers are intertwined with the judgement and attitudes of our society,

informing the availability, quality, and culture of the services (or lack thereof) available to our community.

The UNCRPD provides a clear framework in which both environmental and attitudinal barriers can be addressed in order to ensure access and dignity in public services. In the time available to me, I would like to bring to the Committee's attention a number of concrete steps which must be taken to ensure this reality on the ground:

- 1) **Rights not grace and favour:** As long as our public services continue to operate based on a grace and favour approach, our community will not have parity of access to public services. It is of critical importance that the Optional Protocol of the UNCRPD is ratified during the lifetime of this Oireachtas and that existing disability legislation is reviewed, updated and fully commenced. This includes ensuring that the Disability Act is compliant with the UNCRPD and provides a right to supports and services, not just a right to timely assessment, a right that is presently breached daily across Ireland. Additionally, the EPSEN Act Review must lead to legislation which, when implemented, will ensure every child has the right to access an education, which meets their needs, in a school in their local community.

- 2) **Hear our voice:** We must not only live true to the adage of "nothing about us, without us" but the even simpler principle of "nothing without us". For far too long the voices of disabled people have been absent from public decision-making processes, including but not limited to disability issues themselves. A very recent example of this was significant changes to the SET allocation model in schools which was implemented, following extensive consultation with trade unions and management bodies, but without a single consultation with DPOs or disability groups.

Hearing our voice means much more than simply box-ticking "listening exercises". It means effectively resourcing DPOs and support the development of self-advocacy without the disability community. It means timely, effective consultations which are accessible to all and which value the time, expertise and lived experience of our communities.

- 3) **Disaggregated data and effective planning:** In order to ensure dignity and access to public services, you need to a) have access to data to inform the planning of such services and b) to measure the access and experience of minority groups on the ground. Ireland fails consistently in this regard and the lack of data on Autism, which is not even adequately addressed in the Census question on disability makes our community invisible in policy formulation, in accessing public services and in vindicating our rights to an equitable experience.

- 4) **Training and regulation:** For the entire history of the disabled community, stereotypes, ableism and a deficit-based approach has created barriers to accessing public services and undermined the dignity of our community. We must see a roll-out of neuroaffirmative training, appropriate to role and context, to every public servant in the community. Furthermore we must not see equality of access as the permission to enter but the opportunity to have the same experience. It is a shameful reality that Autistic and disabled people experience discrimination in accessing public services – whether it is mental health services which structurally discriminate against Autistic people or in ourto

approaches which are rooted in behaviourism. We must see proactive regulation to ensure consistent quality and safeguards so that the dignity of Autistic and disabled people is a) guaranteed and b) protected by independent investigatory and complaint mechanisms.

- 5) **Resources:** Of course, fundamentally it is only possible to ensure dignified, equitable access to public services where investment is seen through the rights-lens and not as crumbs from the table or something which is to be praised and lauded. Our community deserves the same chance and the investment to achieve that, whether it is accessible public transport or public buildings or access to the healthcare system, must be seen as non-negotiable, not an optional extra.

Thank you for your time and we look forward to your questions