

#### IRELAND'S AUTISM CHARITY

February 2024

### AsIAm Submission to the National Disability Authority on Proposals for Introducing a new National Disability Strategy

## What changes do you see as important to ensure that disabled people in Ireland are fully included in society in line with the vision of the UNCRPD?

As an organisation which is Autistic-led and centred around supporting and advocating on the rights of Ireland's Autism community, we believe that implementing the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) is critical to realising our objective of ensuring that every Autistic person has the same chance to belong, feel accepted, and to be included in Irish society.

We believe that that it is vital that the Government should implement the UNCRPD Optional Protocol to both expand the rights of disabled people and create a complaint mechanism which will allow individuals to hold the Government to account when appropriate. This should place the onus on the State to introduce laws and policies which are more accessible and inclusive of Autistic people and disabled people, and to consider proactively including the communities affected.

We also note that Article 24 of the UNCRPD, which governs the right of people with disabilities to receive an accessible and inclusive education in their local community has never been fully implemented. In our EPSEN Act Reform submission, we noted that inclusive education should not just be about including people in mainstream classrooms or building Autism classes. Fundamentally, it is about:

- Ensuring families have confidence that their children will have the supports they need in an inclusive setting.
- Ensuring school communities and educational stakeholders who are at the core of our educational system to promote inclusive school cultures.
- Ensuring school buildings embrace the principles of universal design.
- Ensuring access to appropriate school transport systems.

This inclusive approach should also include access to reasonable accommodations, statutory guidelines that regulate practices like Codes of Behaviour, seclusion and restraint, and reduced timetables, integrating individualised supports such as Special Needs Assistants, and statutorily recognising Individualised Education Plans *inter alia*.

We would also like to highlight that the UNCRPD requires Government and State agencies to consult and involve disabled people, including Autistic people, and DPOs prior to any laws or policies being drafted. It can cause undue stress and concern when a proposal is presented which has not been created in consultation with disabled people. Linking in with the people affected by these documents also increases the effectiveness of such laws and policies.

There are many issues for Autistic people and the disabled community at large with accessing services. These issues range from inadequate staffing, the cost of securing private services and supports, lack of available services in certain areas, and navigating gaps and barriers in provision when accessing available services. We would like to see these problems addressed by any future policy that the DCEDIY publishes.

We would also like to see that services and supports are fully accessible to Autistic and disabled people, complying with Universal Design Principles. This will mean that people who are sensitive to certain sensory experiences will be able to engage with all the services that they need to fully participate in society. It is an important part of the UNCRPD to ensure that barriers for disabled people are removed and this is one way in which this can be done.

We particularly stress that all 109 recommendations of the Final Report of the Joint Oireachtas Committee on Autism should be implemented by the Government. It is critical that the Government implement these recommendations across all the relevant Departments and State agencies. If Ireland wishes to create an equal society for all Autistic people and to ensure the entire Autism community gets the same chance to belong, feel accepted, and be included across all aspects of Irish society these recommendations must become central to government policy.

#### What needs to happen for these changes to be achieved?

For these changes to be achieved, legislative action is needed in implementing the following:

- Ratifying the UNCRPD Optional Protocol;
- Fully implementing the Joint Oireachtas Committee on Autism's Final Report recommendations:
- Introducing an Autism Innovation Strategy on a legislative footing which grants our statutory protection;
- Ensuring that Public Sector Duty obligations are universally applied across all State and Government Departments and Agencies;

AsIAm highlights that a new National Disability Strategy should work with and complement disability-specific strategies. We have long called for a National Autism Strategy to be introduced and be made law, like similar strategies in other countries such as Scotland and Malta. In addition to fully implementing the Joint Oireachtas Committee on Autism's Report's Final Recommendations, AsIAm have also made recommendations on how Government can better support Autistic people and families in Ireland through our submission on the Autism Innovation Strategy.

Specifically, what can be done to improve the lives of Autistic people is to ensure access to Autism and disability equality training for all public sector staff. We often find that Autistic people have difficulties arising from a lack of understanding by public sector staff that they encounter. This may cause them to no longer be able to avail of certain services or in some cases cause additional stress and anxiety. Providing training should go some way to assuring our community that they will be supported to access services and supports in their local community.

We at AsIAm believe that developing a "one-stop-shop" for Autistic people would be the most effective way to address some of the issues highlighted earlier. This should ensure that Autistic people find their supports accessible and in a central place where they be supported across the life cycle. The idea behind a one-stop-shop is that all the supports an Autistic person could need, from in-person supports, supporting with understanding autism, with managing aspects of being autistic would all be contained in the one location. The one-stop-shop model of supporting Autistic people is currently in place in Scotland via the organisation Scottish Autism and we call for a model of similar supports to be set up in Ireland to support members of our community.

We also know from a recent EU-wide survey that Ireland is the loneliest country in the European Union with 1 in 5 people feeling lonely all the time. Recent British research found that disabled people are almost twice as likely to be chronically lonely than non-disabled people. A successful strategy must see the implementation of an action plan to combat loneliness and isolation as committed to by Government in *The Roadmap for Social Inclusion* in 2019 and again in the *Programme for Government* in 2020. This strategy must have a specific focus on how to reduce the prevalence of chronic loneliness among disabled people that considers the barriers to social inclusion and wellbeing that disabled people face. These barriers to wellbeing and social inclusion include a lack of access to transport, economic constraints, or sensory needs. While also adequately resourcing increased access to services and supports to address this issue and data collection to allow for better knowledge on the prevalence of loneliness and social exclusion experienced by disabled people as well as the impacts of the supports implemented.

# What would a successfully implemented strategy look like? For example, how do you think life should have improved for disabled people in Ireland at the end of a five-year strategy?

If these changes were implemented in five years, we could expect to see many changes in the lives of Autistic people. In addition to the introduction of the National Disability Strategy, we believe that fully implementing the Joint Oireachtas Committee on Autism Final Report's recommendations and setting up the Autism Innovation Strategy would also achieve the following;

More Autistic people will receive timely access to services and supports they need, including access to supports such as Childrens Disability Network Teams, Assessment of Needs, and access to other services such as psychologists, Speech and Language Therapists, Occupational Therapists, and to disability and respite services within the public health system. With greater access to supports to meet increased demand, this would hopefully mean that fewer in our community would be on waiting lists for diagnoses, therapies, and other supports. Autistic people would be able to access more of their healthcare needs by ensuring hospitals and clinics are accessible, that doctors, nurses, and medical staff are trained in best practices in disability and Autism equality and promoting neuro-affirmative practices in the medical sector.

More Autistic people would receive an accessible education in their local community that meets their needs and engages their interests in more inclusive environments, but also ensuring that every Autistic person has access to a school place with any supports they need. This can be achieved through expanding supports and making sure every child has a place that meets their needs, significantly reducing pupil-teacher ratios, changing mindsets among stakeholders to support inclusive education, creating adaptable and flexible curricula and pedagogies, supporting greater provision of reasonable accommodations for pupils who need additional support, and in-person supports such as Special Needs Assistants and Special Education Teachers are available to pupils who need these supports.

We would see an increased rate of employment of Autistic people across all sectors through targeted campaigns by government and the private sector.

We would see that the impact of actions taken within the Disability Strategy would help to tackle misconceptions, stigma and discrimination experienced by disabled people. Including a **decrease in the numbers of the following**, which AsIAm records in our annual Same Chance Report, which surveyed around 1,000 Autistic people and/or their families:

- 86% do not believe they have the same chance in Irish society;
- 39% do not feel safe and protected in their community;
- 61% did not believe the education system is inclusive of Autistic people based on their experiences;

- 68% are on waiting lists to access services;
- 26% report that their present housing situation does not meet their needs;
- 75% did not believe the health system is inclusive of Autistic people based on their experiences;
- 78% did not believe the social protection system is inclusive of Autistic people based on their experiences;
- 70% of children represented in the report are not presently receiving supports from their HSE Children's Disability Network Team (CDNT).

## If you have any other views that are relevant to the new National Disability Strategy, please tell us?

As an organisation supporting Autistic people and our wider community, our experience of engaging with previous disability strategies has been that whilst these were very ambitious plans for their time, lack of resources and coordination across Government departments and State agencies has meant that this translated to little meaningful change for disabled people, including Autistic people. We also believe that it was difficult to track progress in the Strategy. This is because the Traffic Light system used by some Government departments had the effect of obfuscating the progress of key actions, and as some actions landed across multiple Government departments and State agencies without a coordination mechanism to effectively deliver these actions.

We welcome the Department's intent to deliver a more focused National Disability Strategy with more targeted actions involving more Government Departments and State Agencies. We anticipate that the new Strategy should deliver more impactful changes which help to build a more accessible society. There needs to be more effective monitoring and accountability mechanisms around how actions are taken under the Strategy to ensure effective delivery, and that communities see that these measures make meaningful change on the ground.

We also believe that the themes that have emerged across the strategy – employment and anti-poverty, transport, housing, mobility, wellbeing and social care services, education and training, and independent living in the community – are very timely and broadly capture some of the barriers that many disabled people, including Autistic people, experience across Irish society, and where targeted actions could be particularly impactful. However, within these themes, the Strategy also needs to include measures which recognise the disability community's diversity and intersectionality, such as disabled women and girls, disabled children, disabled older people, the intersection between aging and disability, and recognise and support the work of families and carers who support both our community and other disabled people.