

AsIAm Submission to the Department of Social Protection on their Statement of Strategy 2025-2028

14th March 2025

AsIAm welcomes the opportunity to engage with the Department of Social Protection to support with the development of their new Statement of Strategy for 2025-2028. This submission will seek to establish:

- The context of the Autistic community and how they access the social protection system
- Government commitments to make changes to our social welfare system
- Autism Innovation Strategy
- Recommendations for the Statement of Strategy 2025-2028

About AslAm

AsIAm is Ireland's Autism Charity, we are dedicated to removing the invisible barriers often faced by Autistic people and families, so that every Autistic person can enjoy the same chance in society. Our vision is for an Ireland to be a country where every Autistic person is accepted as they are. Our purpose is to create an inclusive society for Autistic person that is accessible, accepting and affirming.

Introduction

The true measure of any society is based on how it treats its most vulnerable citizens. Within the last two years, rising inflation within the Irish economy has affected everyone's quality of life but has particularly impacted some groups within society more. The Autistic community have been among those worst hit by these sharp rises in living costs. During this period of high inflationary pressures on everyday goods and services, many within the Autistic community experienced difficulties in paying for everyday necessities such as food, heating, electricity, and clothing. Community members also often struggle with meeting extra expenses including accessing supports and services. This often forces families to take on more caring duties or to cut back on work hours to support an Autistic family member. We also understand that many in our community are more likely to experience poverty and financial hardship. This leaves Autistic people and families all-too-often having to count the cost of not having the same chance in society. As an organisation, we believe that living in poverty should not be an inevitable part of being Autistic or raising an Autistic child. Families raising an Autistic child should be recognised, supported, and fairly compensated by the State.

Social protection is a vital social safety net for many Autistic people and families, and community members rely on access to payments like Domiciliary Care Allowance, Disability Allowance and Carers Allowance as an important source of income. The recent publication of the Autism Innovation Strategy highlights key actions which can improve access to social protection services, and make securing supports more accessible for our community. These objectives as highlighted within the Autism Innovation Strategy if implemented would provide for a more accessible and user-friendly system for the Autistic community. As well as these actions under the Autism Innovation Strategy, Ireland as a signatory to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) under Article 28 has an obligation to ensure disabled people have access to an adequate standard of living and social protection, which includes the safeguarding and promoting of this right. Article 19 of the Convention also states that disabled people have the right to live independently in the community with the right supports and to have choice and control over how they want

to live. This submission identifies several key recommendations which if implemented would support the upholding of these rights.

Poverty

From our recently conducted annual Same Chance Report it was found that 64% of Autistic people and families did not believe the social protection system was inclusive or accessible of Autistic people. An example of this inaccessibility can include, but are not limited to:

- Needing to provide extensive medical information during the application process.
- Having to go through an appeals process after an initial rejection.
- Intreo offices not being accessible to Autistic people's sensory needs.
- A lack of Autism training among Intreo staff.

For further context, according to the <u>Survey on Income and Living Conditions (SILC)</u> 2023, the poverty rate for people who are unable to work due to Disability is 27% compared to 6% for non-Disabled people. More than this, the SILC results for 2023 show that 45% of Disabled people who are long term unemployed are living in deprivation compared 12% of those who are working.

Employment

In 2024, the Department for Social Protection published its proposals to reform
Disability Income supports (a proposal which was also known as a Green Paper),
received considerable engagement from community members and groups across civil
society. AsIAm conducted an extensive survey (303 responses) from our community
members to gather perspectives, insights and opinions about the Green Paper
proposal. Of the respondents to this survey, 67% of people did not think that the current
way in which social protection was provided was either appropriate or adequate. In
addition to this research conducted by IrishJobs.ie, it was found that 85% of Autistic
adults were either unemployed or underemployed. Such a stark statistic has a farreaching impact for the Autistic community, for example underemployment or lack of
employment creates missed opportunities for Autistic people in terms of employment,
recreational activities and social opportunities. Having access to these opportunities

create dignity, meaning and a sense of purpose for many Autistic people, without which, Autistic people are more likely to experience loneliness and social exclusion, as well as poverty. There is a clear link between being out of work and living in deprivation. We also learned that this is part of a wider interconnected relationship between poverty and disability. These facts combined mean that Autistic people are more likely not to have enough money to cover their needs such as heating and electricity, the cost of housing, access to transport and medical expenses. Autistic people may also incur other costs that other cohorts accessing social protection would not, including purchasing assistive technology, therapeutic supports, particular clothing and food to meet the sensory needs of an individual. Living in poverty also means that people cannot always make the same choices in many of these areas of life. For these reasons, an expanded scheme to support Disabled people to access <u>personalised budgets</u> to include Autistic people would make real progress in addressing these barriers and gaps in supports.

When we asked our community members in our Same Chance Report for their experiences of employment, we see a variety of experiences, with some community members working part time (11%), working full time (22%), not working currently (17%) and looking for work (5%). It was also found that 70% of people were accessing no supports or accommodations in the workplace. Community members told us that they often had negative experiences of employment for a variety of reasons, such as:

- Fear of losing secondary benefits such as Free Travel and Medical Card
- Managing one or more other Disabilities or illnesses
- Barriers with the recruitment process, such as job applications and interviews
- Lack of jobs available that match their skills, interests and qualifications
- Recovering from illness or burnout
- Experiences of discrimination, ill-treatment or lack of supports in the workplace

Although employment does not fall directly within the remit of the Department for Social Protection, the Department does run several schemes to assist people to access work. Intreo centres which assist jobseekers to access jobs as well as process social welfare claims are in every community across Ireland and are accessed every day. It is imperative that all Intreo centres are designed with universal design principles at the

forefront, to ensure that the physical space is welcoming of Autistic people and their families when engaging with Intreo services. It is also key to ensure that workers in these centres have the appropriate training to best understand the needs of Autistic people and how to support those needs.

Assessing Disability to Qualify for Social Protection Payments

A key barrier to accessing support for many Autistic people lies with the assessment process, which we believe is out of step with Articles 5 and 28 of the United Nations Convention on the Rights of Persons with Disabilities. Through AslAm's engagement with the Autistic community, many Autistic people find navigating the system around accessing Disability payments to be intrusive, as it places the burden on the person applying for the payments to prove the extent to which how their difference or Disability impacts their day-to-day life, often with no supports in navigating the process. Many Autistic people and their families find the application and appeals processes upsetting. Some feel humiliated and treated with suspicion at each step. They often feel that their stories are not believed or are not treated with dignity throughout the process. The need to disclose sensitive personal information or recount distressing events to prove eligibility for support can make the process even more difficult or traumatising.

This can cause considerable distress and anxiety and take its toll on many Autistic and Disabled peoples' health and wellbeing. It also does not consider the full range of barriers that Autistic and Disabled people already experience living in society. These barriers include navigating the gaps in support provision between education and employment and increased exposure to poverty, loneliness, and social exclusion. It also does not factor that many Autistic people face barriers in keeping up with the Department's expectations when applying for supports, and that the process may not always factor Autistic people's communication differences and access needs, and differences in sensory processing and in processing information.

There are significant difficulties for many Autistic and Disabled people in securing a diagnosis in the first instance. Moreover, as there are no pathways within the public healthcare system for Autistic adults to secure an official diagnosis through an autism

assessment or after-care support, there may be often significant costs and waiting lists to securing these supports privately.

Information contained in many diagnosis reports may not be up-to-date or may be written when perceptions or attitudes towards Autistic people were different to where they are presently. This is arising as more Autistic people are now speaking openly about their living experiences and feel more comfortable to be open about identifying as Autistic. These reports may portray a more medicalised perception of Autism, which may portray Autism as a 'disorder' rather than as a difference, neurotype, or Disability which many in the community prefer.

Prevailing attitudes towards Disability, and to neurodevelopmental differences like

Autism, can also influence whether an Autistic person might feel comfortable or safe to
be open about being Autistic. Progress in workplace diversity and inclusion has not yet
translated to significantly increased understanding of Autism, Disability, and
neurodiversity among employers. This can make it harder for many Autistic people to be
open about being themselves with prospective employers. In our Autism in the
Workplace Report, it was found that 72% of people felt that they have to 'mask' or hide
their identity and support needs associated with being Autistic to fit in at work, which
includes finding work or looking for work. This shows that many people in our
community believe that there is significant stigma around Disability and around
differences like Autism, and they are worried that they would be discriminated against
or treated differently if they take the decision to disclose that they are Autistic.

AsIAm finds that the Department of Social Protection's current approach to assessing Disability, often leads to disparities in terms of who qualifies for benefits or supports, and inconsistencies around who may be entitled to support. Often, whether an Autistic person is entitled to access Disability social protection payments could hinge on the 'functioning label' that an Autistic person is perceived to fall into, with little input from the Autistic person themselves or understanding about their experiences. It also often does not consider that attitudes towards Disability and neurodiversity are changing as Ireland has ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). This does not comply with Article 28 of the UNCRPD, as it leaves many Autistic and Disabled people without any entitlement to support if their access

needs do not neatly fit into narrowly defined, often medicalised, conceptions of their Disability or difference. These conceptions may often portray Autism as a 'disorder' needing to be 'cured' or 'treated' or seeing a person's accessibility requirements as a 'deficit'.

The European Disability Forum (EDF), highlight the barriers to accessing supports in their report on Social Protection across the European Union (EU). The Report highlights the barriers within the medical approach taken by some EU Member States, including Ireland, and its approach to Disability assessments:

The European Disability Forum (EDF) state that: "The challenges associated with Disability assessment are numerous. To begin with, the process can be lengthy and arduous and, in some cases, undignified. The methods used can also be restrictive and fail to consider the true barriers people face in their daily lives as persons with disabilities. An assessment that does not truly consider the societal barriers the person with disabilities faces, combined with what are often restrictive social protection budgets foreseen for persons with disabilities, result in many persons with disabilities not getting the support they need after being assessed as having a Disability. We also see particular difficulties for persons with "hidden" or "invisible" disabilities who can be misdiagnosed on not diagnosed at all, meaning they lose all entitlement to the support and services they require. Women are also more likely than men to have a Disability or a condition misdiagnosed or left undiagnosed."

The Cost of Disability

In 2021, the Department of Social Protection and Indecon produced a report on the Cost of Disability in Ireland. This report set out the significant additional cost of living that many Disabled people, including Autistic people, experience in Irish society. The report highlights that Disabled people have a substantially lower income compared to non-Disabled or neurotypical people, with many Disabled people receiving an annual income of less than €8,000 per year, meaning they often experience hardship and struggle to make ends meet. The report also estimates that the average additional costs of living as a Disabled person in Irish society is between €9,500 and €11,700 per year. This includes unmet needs of between €2,522 and €3,821 per year.

Additionally, other organisations such as the ESRI (Economic Social and Research Institute) and the OECD (Organisation for Economic and Cooperative Development) have highlighted the extent to which Disabled people are at a higher risk of poverty and social exclusion in Ireland. The ESRI have highlighted that households with one or more Disabled adults experience some of the highest poverty levels in the State, and this is demonstrated in its recent *Thematic Report on Poverty and Social Inclusion Indicators*. The ESRI Report found that Ireland ranks among the five poorest performing countries in the European Union for addressing "at risk of poverty" and severe material deprivation for Disabled people and their wider communities. ATU researcher Dr Áine Roddy, in 2018 published research which sought to estimate the costs of living of raising an Autistic person in Irish society. This research highlighted that costs can be as high as €28,464.89 per year, which can arise due to the cumulative loss of earnings experienced by families who may have to reduce their working hours or leave work to support their family member.

Autism Innovation Strategy

In 2024, Ireland published its first Autism Innovation Strategy. This strategy is an 18-month strategy that has 83 actions across the whole of Government and wider state agencies. There are five key actions required by the Department for Social Protection:

- 1. To better support Autistic people using Citizens Information Services and the National Advocacy Service for People with Disabilities, we will support staff in Citizens Information Board-funded companies to access and engage with the new public sector e-learning training module being developed on disability equality, which includes consideration of the unique needs of autistic people. This foundational learning tool will provide a basis for identifying further actions and supports that may be required.
- To ensure the accessibility and user friendliness of MyWelfare scheme applications, we will consult with autistic customers and other people with a disability as part of the process to digitalise applications for disability schemes on MyWelfare.
- 3. To ensure that autistic people have access to up-to-date information on relevant services and supports, we will signpost and provide links to relevant information

for autistic people. This will be provided on citizensinformation.ie and in the Guide to entitlements for people with disabilities. It will cover information on services and supports (including assistive technology) hosted on other public sector sites.

- 4. To ensure that Intreo (the Public Employment Service) effectively supports employment service staff to address employment opportunities and challenges for people with disabilities, including autistic people, we will review our disability awareness training.
- 5. To ensure a supportive environment for autistic people and others with sensory processing differences in accessing and using Intreo employment services, we will ensure that a quiet, calm room is available in each Intreo office by the end of the first quarter of 2025.

All these actions will require significant collaboration with other Government departments and agencies, and it is important that these actions are embedded within the Department's workplan for the next 3 years. The Autism Innovation Strategy also has an Oversight Group that is tasked with monitoring the progress of these actions. We believe that it is important for all Government departments and State agencies listed in the strategy take positive and effective action to the strategy's full implementation.

Programme for Government

The new Programme for Government, which was released in January 2025, made several welcome commitments around social protection including a commitment to fully abolish the means test for Carers Allowance. This has been a long standing ask of AsIAm's as well as other organisations in the Disability sector. Carers are estimated to provide a value of €20 billion per year to the State, and actions like will make considerable progress to both acknowledge, and to recognise and meaningfully support their vital work is incredibly welcome.

Other key commitments by Government include:

 Introduce a permanent Annual Cost of Disability Support Payment with a view to incrementally increasing this payment in line with inflation and living costs.

- Reform the Disability Allowance Payment and remove anomalies in the current means test for the payment.
- Progressively increase weekly Disability Payments and the Domiciliary Care
 Allowance to meet rises in inflation and living costs.
- Review the minimum hours requirement under the Wage Subsidy Scheme for people with disabilities and examine an increase to the payment rate.
- Expand and build on successful programmes like WorkAbility, Employability, and the new Work and Access Programme to support Disabled people into employment.
- Examine the 'ability to work' criteria for certain payments and ensure that
 ongoing medical assessments are not carried out in respect of people with
 lifelong conditions that are not going to change.
- Protect the Free Travel Pass and examine extending it to children in receipt of Domiciliary Care Allowance.
- Promote training initiatives to raise awareness and the understanding of disabilities amongst Intreo staff.

Recommendations

- Provide a top-up payment to families with a child in receipt of Domiciliary_Care
 Allowance directly through the Child Benefit Scheme.
- Mandate Autism Understanding and Disability Equality training for all Intreo staff, as well as adjusting all Intreo buildings and services to make them fully accessible for Autistic people with a focus on universal design.
- Take a holistic approach to equality-proofing and Disability-proofing proposals
 for new payments so that changes to payments do not disproportionately impact
 marginalised groups in Irish society and deepen poverty and social exclusion, for
 groups such as Autistic people, family carers, lone parents, etc.
- Mandate employers to engage with employment services for Disabled people by making reasonable accommodations, Autism training and implementing quotas for hiring Disabled staff.

- Develop a portal for employers and employees to have accessible information around the workplace supports or accommodations available for their difference or Disability.
- Reduce waiting times for people trying to access Disability type social protection payments_and reducing excessive demands for reassessment. Continued assessment should be avoided where possible so as not to place the Disabled person under unnecessary stress.
- Establish a cross-education and employment system, in keeping with Universal Design principles, which Autistic people and Disabled people can register at any stage of their education or career if they have a proof of their Disability, or if they are considering or in the process of pursuing a diagnosis.
- Support other organisations, including Disabled Persons Organisations (DPOs)
 and other organisations who work in the Community and Voluntary sector, to
 support Autistic and Disabled people who are looking for work, both financially
 and to build capacity to support people who wish to find work which meets their
 skills, qualifications, and access needs.
- Introduce a universal baseline Cost of Disability payment for all Disabled people
 which is not means tested and is directed towards addressing the additional
 hidden costs of Disability.
- The Department of Social Protection should take a neuro-affirmative approach
 to Disability assessment and to take the diversity of needs within the Autistic
 community into account when making decisions around access to payments
 and supports.
- Supports provided by the Department of Social Protection should reflect the full
 diversity of living experience of Autistic people, as well as other Disabled and
 neurodivergent people. All Disabled people, regardless of levels of support need,
 should be entitled to access reasonable accommodations at work if they so
 choose.
- Provide personal supports, such as Access Officers, who can collaborate with Autistic employees and Disabled employees to figure out what supports they want at the start of the application process.

- The application process should take a person-centred, rights-based approach, designed in keeping with Universal Design Principles, and should prioritise the applicant's dignity, agency, and preferences at all stages of the process.
- The Department of Social Protection should accept a wider range of options
 related to evidence of Disability for applications to the Fund, in recognising that
 not every Disabled person has equal access to services or supports. They should
 also ensure that people at all stages of their Disability or Autism journey can
 access accommodations at work.
- Any requirement to produce information should not place either Autistic people
 or Disabled people under pressure to prove how their difference or Disability
 impacts them at work or living in society. The aim should be on the Department
 to provide for the individual's support needs, which will in turn help them into
 work.
- Reimburse applicants for out-of-pocket expenses related to securing accommodations within the Reasonable Accommodations, including medical and therapist appointments, doctor's letters, etc.
- By improving co-ordination with the Department for Enterprise, Trade and Employment, mandate employers to engage with employment services for Disabled people by making reasonable accommodations, Autism training, and inclusive hiring practices.
- Engage in a cross-departmental review of the Government commitment to rollout a 6% quota for hiring Disabled people, for all State agencies.
- By working with the Department of Enterprise, Trade and Employment gradually implement a similar quota into the private sector
- Standardise the age ranges between Domiciliary Care Allowance and Disability Allowance from 16 to 18.
 - Introduce this standardisation on a 'no-loss' basis, to ensure families do not suffer a loss of income from this change. This may be done by providing a higher rate of DCA to those with children aged 16 and 17.