

July 2025

AslAm Submission to the Department of Social Protection on the Successor Strategy to the *Roadmap for Social Inclusion*

AsIAm, Ireland's Autism Charity, welcomes the opportunity to engage with the Department of Social Protection in developing a new strategy to succeed the *Roadmap for Social Inclusion*. Building on recent engagements with the Department, this is a timely opportunity to highlight the barriers faced by Autistic people and Disabled people in securing an adequate income within the social protection system.

This consultation is particularly important given the impact of previous Department initiatives, such as the *Cost of Disability Report* and the *Green Paper on Disability Reform:* A *Public Consultation to Reform Disability Payments in Ireland*, on shaping public debate on disability and social protection in recent years.

It is also critical that the Department takes concrete action to reform disability-related social protection payments to better align with Article 28 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). These reforms must make payments more accessible and inclusive for our community, cover the additional costs associated with living as an Autistic or Disabled person, incorporate inclusive eligibility criteria and address systemic barriers that persist within the current framework.

This submission will highlight the following:

The Financial Pressures Faced by Autistic People and Families;

- Measuring Ireland's Progress on Tackling Poverty, Social Exclusion and the Disability Employment Gap;
- The Green Paper on Disability Reform;
- Counting the Costs of Being Autistic or Disabled in Irish Society;
- Community Experiences in Dealing with the Department and Employment Services;
- Inconsistencies in Disability Assessments and their Impact in Accessing Disability Supports;
- Experiences and Barriers to Employment for Autistic People;
- Public Attitudes and the Role of Social Protection;
- Independent Living and Access to Housing;
- Promoting Autistic People's Wellbeing and Tackling the Effects of Isolation and Social Exclusion;
- Programme for Government Commitments on Disability and Social Protection;
- Commitments under the Autism Innovation Strategy;
- Recommendations for the Next Roadmap for Social Inclusion;

About AsIAm

AsIAm is Ireland's Autism Charity, we are dedicated to removing the invisible barriers often experienced 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. AsIAm are an Autistic-led organisation who is a Disabled Person's Organisation (DPO) and a member of the DPO Network.

The Financial Pressures Facing Autistic People and Families

Over the years, rising inflation and persistent increases in the cost of everyday goods and services have affected the quality of life and wellbeing of all citizens. However, some groups, including the Autistic and Disabled communities, have been particularly squeezed by these pressures. These communities already face significant additional costs due to their support needs, and inflation has made it even more difficult to afford essentials such as food, heating, electricity, and clothing. These are often items they require in greater quantities or in specific forms, where price increases have been especially pronounced, which we will explore in more detail later in this submission.

Autistic people and families also face significant additional costs directly related to being Autistic or raising an Autistic person, including the cost of accessing services and supports. Meeting these extensive financial demands often leaves families with having to make difficult decisions when supporting an Autistic person, such as taking on more caregiving responsibilities or reducing paid working hours. Our engagement with the Autistic community shows that they are more likely to experience poverty, financial hardship, and social exclusion, with many seeing a decline in income and living standards due to having to meet these extra costs.

Our most recent *Same Chance Report* found that 79% of community members have additional costs because they or their family member is Autistic.¹ These costs can take several forms, including:

- Medical expenses, such accessing therapies through private clinics;
- Increased transport costs;
- Buying sensory-friendly clothing, or additional clothing;
- Adapting the home to make it more accessible;
- Loss of income due to caregiving responsibilities;

¹ AslAm, 'Same Chance Report', https://cdn.prod.website-files.com/6537ebfefba7b3c24a18e646/67e572276f39ff1d6d830135_Version%203%20Digital%20Full%20AslAm%20 Same%20Chance%20Report.pdf (accessed 26 Jun 2025)

This year's Same Chance Report also highlights the impact of social exclusion on our community across many areas of Irish society, including:

- 70% do not believe the education system is inclusive of Autistic people.
- 55% experience barriers to accessing mental health services on the grounds of being Autistic.
- 69% of children represented in the report are not currently receiving supports from their local HSE Children's Disability Network Team (CDNT).
- 33% report that their family's current housing situation does not meet their needs.²

A 2024 Report by the Economic and Social Research Institute (ESRI), *Poverty, income inequality and living standards in Ireland,* found that almost 1 in 4 households with a Disabled person were living in deprivation.³ This means these households cannot afford goods and services that are considered standard in Irish society - These goods and services can include heating, fuel, jackets, hot meals, furniture, and the ability to cover unexpected expenses like family emergencies – putting them at increased risk of poverty and social exclusion. It also found that households that include a Disabled person are twice as likely to experience deprivation, with 16.3% living at risk of poverty.⁴ Additionally, a recent Report from TASC, the Think-Tank for Action on Social Change, found that 44.3% of those unemployed Disabled people are in the bottom income group⁵, further highlighting the scale of exclusion faced by Disabled people and families, as well as within our community.

This often leaves Autistic people and families bearing the cost of not having the same chance to belong, be accepted, and fully participate in Irish society. As an organisation,

² AslAm, 'Same Chance Report', https://cdn.prod.website-files.com/6537ebfefba7b3c24a18e646/67e572276f39ff1d6d830135_Version%203%20Digital%20Full%20AslAm%20Same%20Chance%20Report.pdf (accessed 26 Jun 2025)

³ Economic Social and Research Institute, 'Poverty, Income Inequality and Living Standards: Fourth Annual Report,' p. 16, https://www.esri.ie/system/files/publications/JR7_1.pdf (accessed 26 Jun 2025)

⁴ Economic Social and Research Institute, 'Poverty, Income Inequality and Living Standards: Fourth Annual Report,' p. 16, https://www.esri.ie/system/files/publications/JR7_1.pdf (accessed 26 Jun 2025)

⁵ Think-Tank for Action on Social Change (TASC), 'The State We are In: Inequality in Ireland 2025', p. 15 https://www.tasc.ie/assets/files/pdf/tasc_the_state_we_are_in_2025.pdf (accessed 26 Jun 2025).

AsIAm believes that living in poverty or experiencing social exclusion should not be an inevitable part of being Autistic or raising an Autistic child. The State must recognise, support, and fairly compensate Autistic individuals and their families – especially for the additional costs arising from their differences, disabilities, or support needs.

Social protection is a vital social safety net for many Autistic people and families. We understand that community members typically rely on accessing payments like Domiciliary Care Allowance, Carers Allowance and Disability Allowance as essential sources of income. Under Article 28 of the UN Convention on the Rights of Persons with Disabilities, Ireland has an obligation to "an adequate standard of living for themselves and their families, including adequate food, clothing and housing, and to the continuous improvement of living conditions, and shall take appropriate steps to safeguard and promote the realisation of this right without discrimination on the basis of disability." 6 This includes support for Disabled women and girls, older people, families covering disability-related expenses, access to housing, and retirement supports. Additionally, Article 19 of the UNCRPD states that all Disabled people have the right "to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community"7. This includes the right to choose where and with who they want to live, having "access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community".

While the stated ambition of the *Roadmap for Social Inclusion 2020–2025* is to make Ireland one of the top five EU countries by reducing the proportion of people at risk of poverty and social exclusion from 21.1% (in 2018) to 16.7% by 2025,8 the current reality

⁶ Article 28, UN Convention on the Rights of Persons with Disabilities, <u>Article 28 – Adequate standard of living and</u> social protection | United Nations Enable (accessed 26 Jun 2025)

⁷ Article 19, UN Convention on the Rights of Persons with Disabilities', <u>Article 19 – Living independently and being included in the community</u> <u>United Nations Enable</u>, (accessed 26 Jun 2025)

⁸ Department of Social Protection, 'Roadmap for Social Inclusion 2020 - 2025 Ambition, Goals, Commitments', p. 14 https://assets.gov.ie/static/documents/roadmap-for-social-inclusion-2020-2025-ambition-goals-commitments.pdf (accessed 26 Jun 2025)

for many Autistic people and families is deeply concerning. Recent evidence shows that disability-related poverty has deepened for many Autistic and Disabled people and families across Ireland, particularly as many community members rely on social transfers as a key source of income. Our Same Chance Report found that 64% of Autistic people and families did not believe that that social protection system was accessible or inclusive of Autistic people.⁹

Community members identified several barriers, including the need to provide extensive medical documentation to prove disability, having to undergo complex and prolonged appeals processes, the inaccessibility of Intreo offices, and a general lack of understanding among Intreo and Department of Social Protection staff.

Supporting these concerns, a recent *Irish Times* article reported that between 2020 and 2024, more than 34% of all disability payment applications made by families were rejected. However, over 60% of parents of Disabled children succeeded on appeal after initially being denied care support payments.¹⁰

⁹⁹ AslAm, Same Chance Report 2025, p.40, https://cdn.prod.website-files.com/6537ebfefba7b3c24a18e646/67e572276f39ff1d6d830135_Version%203%20Digital%20Full%20AslAm%20 Same%20Chance%20Report.pdf (accessed 26 Jun 2025).

¹⁰ Coyne, E., 'Appeals against initial refusal of Domiciliary Care Allowance successful 60% of time', *The Irish Times*, https://www.irishtimes.com/politics/2025/06/18/appeals-against-initial-refusal-of-domiciliary-care-allowance-successful-60-of-time/ 18 Jun 2025, accessed 26 Jun 2025.

Measuring Ireland's Progress in Tackling Poverty, Social Exclusion and the Disability Employment Gap

Ireland has clear international obligations in terms of tackling barriers faced by the Autistic and Disabled communities, following Ireland's ratification of the UNCRPD in 2018. Despite this, numerous monitoring bodies have found that despite progress in this area, the Autistic and Disabled communities have been further left behind.

Organisations like the European Commission, the ESRI (Economic and Social Research Institute) and the Central Statistics Office have closely monitored policy developments around social protection and securing an adequate income, and its recent findings

reveal the scale of barriers experienced by Disabled people, including Autistic people.

The most recent *European Semester Report for Ireland* published by the European Commission, revealed that Ireland has one of the highest disability employment gaps in the EU, with 38.2% of Disabled people experiencing unemployment and underemployment. The Commission cited barriers to accessing education, lack of access to reasonable accommodation at work, and discrimination as key reasons. This stands in stark contrast to the *Roadmap's* commitment to increase the employment rate of Disabled people to 33% by 2027. The *Semester Report* also highlighted that 30.1% of Disabled people were considered at risk of poverty and social exclusion, and 4 times as many Disabled people could not afford everyday goods compared with the general population.

Whilst the Commission acknowledged that one-off cost-of-living measures in recent Budgets gave some relief, they expressed concern that the social protection system was not adequately compensating for the additional costs of disability and that recent

¹¹ European Commission, 2025 Country Report – Ireland, p. 90, <u>7ec5fe18-b881-4140-b86a-7b22cb7a8580_en</u> (accessed 20 Jun 2025).

¹² European Commission, 2025 Country Report – Ireland, p. 90, <u>7ec5fe18-b881-4140-b86a-7b22cb7a8580_en</u> (accessed 20 Jun 2025).

¹³Department of Social Protection, 'Roadmap for Social Inclusion 2020 - 2025 Ambition, Goals, Commitments', p. 57 https://assets.gov.ie/static/documents/roadmap-for-social-inclusion-2020-2025-ambition-goals-commitments.pdf (accessed 26 Jun 2025)

¹⁴ European Commission, 2025 Country Report – Ireland, p. 96, <u>7ec5fe18-b881-4140-b86a-7b22cb7a8580_en</u> (accessed 20 Jun 2025).

payment increases were not keeping pace with inflation.¹⁵ The 2024 Survey on Income and Living Conditions (SILC) from the Central Statistics Office revealed that 32.5% of Disabled people who were unable to work were at risk of poverty compared to 5.4% who were employed, and almost 1 in 5 Disabled people of working age (18-66) were living in deprivation and consistent poverty.¹⁶ Alarmingly, without the one-off cost of disability measures from recent Budgets, it found that 37.4% of Disabled people would be at risk of poverty¹⁷ in keeping with Disabled peoples' poverty rates being between 2.5 and 4 times the national average. Speaking to this precarity, the European Commission highlighted that:

"The main form of financial support – the disability allowance – has not increased in line with inflation. The EUR 12 increase in the maximum personal rate of weekly disability payments came into effect in January 2025. However, the Disability Federation of Ireland estimates that a further increase of EUR 20 per week is the absolute minimum required for the disability allowance to keep pace with inflation".¹⁸

In its analysis of Budget 2025, Social Justice Ireland critiqued the Department's decision to not introduce a bespoke Cost of Disability payment stating that:

"We regret that Budget 2025 failed to take the necessary steps to improve services and funding for children and adults with a disability. The failure of Budget 2025 to introduce an ongoing cost of disability payment despite the findings of the Cost of Disability in Ireland report is concerning. The costs of disability are clear, and they are not one off. If disabled people are to be equal

¹⁵ European Commission, 2025 Country Report – Ireland, p. 96, <u>7ec5fe18-b881-4140-b86a-7b22cb7a8580_en</u> (accessed 20 Jun 2025).

¹⁶ Central Statistics Office, 2024 Survey on Income and Living Conditions, https://www.cso.ie/en/releasesandpublications/ep/p-silc/surveyonincomeandlivingconditionssilc2024/poverty/ (accessed 26 Jun 2025).

¹⁷ Central Statistics Office, 2024 Survey on Income and Living Conditions, https://www.cso.ie/en/releasesandpublications/ep/p-

silc/surveyonincomeandlivingconditionssilc2024/impactofcostoflivingmeasuresonpovertyandincome/ (accessed 26 Jun 2025)

¹⁸ European Commission, 2025 Country Report – Ireland, p. 97, <u>7ec5fe18-b881-4140-b86a-7b22cb7a8580_en</u> (accessed 20 Jun 2025).

participants in society, the extra costs generated by their disability should not be borne by them alone. Progress on this issue is long overdue."19

Social Justice Ireland argue that a €25 per week increase is necessary to reflect the increased costs for everyday essentials and to gradually index core welfare rates against average earnings²⁰.

The consistently high levels of poverty, social exclusion and material deprivation Disabled people and families experience have also been highlighted by the ESRI (Economic and Social Research Institute) as a pressing issue that demands urgent and comprehensive action from the Department. The ESRI has pointed out that the presence of a Disabled household member is a contributing factor to families experiencing poverty and deprivation regardless of their income. ²¹ EUROSTAT has also found that Ireland ranks 17th out of 27 countries in the European Union for addressing at risk of poverty and severe material deprivation for Disabled people and their wider communities. ²²

The Green Paper on Disability Reform

One of the Department's key proposals in the *Roadmap for Social Inclusion* to address disparities in disability social protection payments is to "Develop and consult on a 'strawman' proposal for the restructuring of long-term disability payments to simplify the system and take account of the concerns expressed in the 'Make Work Pay'

¹⁹ Social Justice Ireland, 'Budget 2025 Analysis and Critique', https://www.socialjustice.ie/system/files/file-uploads/2024-10/Budget%202025%20Analysis%20and%20Critique%20%281%29.pdf (accessed 26 Jun 2025)

²⁰ Social Justice Ireland, "Social Welfare Rates: Budget 2026

The case for benchmarking and indexation ", p. 5, https://www.socialjustice.ie/system/files/file-uploads/2025-06/Budget%202026%20Benchmarking%20and%20Indexation%20Final.pdf (accessed 26 Jun 2025)

²¹ ESRI, 'Adjusting Estimates of Poverty for the Cost of Disability',

https://www.ihrec.ie//app/uploads/2025/03/Adjusting-Estimates-of-Poverty-for-the-Cost-of-Disability.pdf (accessed 26 Jun 2025)

²² EUROSTAT, https://ec.europa.eu/eurostat/databrowser/view/hlth_dpe010/default/bar?lang=en accessed 26 Jun 2025

report"²³. This happened in 2023, when the Department of Social Protection published proposals to make changes to Disability social protection payments, known as the *Green Paper on Disability Reform*, which included a Strawman proposal to introduce a 3-tier system of disability payments which aimed to align payments according to level of need. There was considerable debate and discussion among Autistic and Disabled communities, disability and anti-poverty organisations, and wider civil society. These conversations focused not only on the proposal itself, but also on its potential implications for Autistic and Disabled people and their families if implemented.

In forming our response to the *Green Paper* proposals, we surveyed community members to find out their views about the proposal and how they would like to see the social protection system change to better support Autistic people and families. We found that 67% of community members did not find that current social protection payments to be appropriate or adequately meet their needs, ²⁴ and 55% of Autistic people did not feel that the proposed tiers reflected their needs. ²⁵ Community members reflected concerns that support levels were connected to their perceived ability to work, and not their support needs. AslAm highlighted several concerns with the proposals, including the assessment criteria, including that it failed to reflect Autistic people's real costs and experiences and prioritised "capacity to work" over realising rights, dignity and wellbeing.

²³ Department of Social Protection, 'Roadmap for Social Inclusion 2020 - 2025 Ambition, Goals, Commitments', p. 57 https://assets.gov.ie/static/documents/roadmap-for-social-inclusion-2020-2025-ambition-goals-commitments.pdf (accessed 26 Jun 2025)

²⁴ AslAm Submission to the Department of Social Protection on Disability Income Supports Reform, https://cdn.prod.website-

 $[\]frac{\text{files.com/6537ebf5bd64fee2cfd5af24/6632576c36769aa351eb2f9e_AslAm\%20Green\%20Paper\%20Submission.pd}{\underline{f}} \ \ \text{(accessed 26 Jun 2025)}$

²⁵ AsIAm Submission to the Department of Social Protection on Disability Income Supports Reform, https://cdn.prod.website-

 $[\]frac{\text{files.com/6537ebf5bd64fee2cfd5af24/6632576c36769aa351eb2f9e_AslAm\%20Green\%20Paper\%20Submission.pd}{\text{f (accessed 26 Jun 2025)}}$

Counting the Costs of Being Autistic or Disabled in Irish Society

The Center for Inclusive Policy highlights that an inclusive social protection system should incorporate disability assessments that accurately capture a Disabled person's access needs, reflect the diversity of disability-related costs, and support the development of in-kind benefits to meet those needs - such as Personal Assistance, therapies, and medical expenses. Such systems should also eliminate harmful eligibility criteria, actively involve Disabled people in the design and production of social protection policies, and ensure that all processes, including applications, are fully accessible.²⁶

The Autistic community's experiences reveal that many Autistic adults and families find the current social protection system to be often exclusionary and inaccessible – particularly as they struggle to meet everyday expenses and encounter significant barriers in navigating the system. These barriers are compounded by additional costs related to being Autistic or raising an Autistic person, such as assistive technology, therapies, specific "safe foods", or sensory items.

The scale of disability-related costs borne by Autistic people and families is highlighted by research published by ATU Sligo researcher Dr Áine Roddy which estimated the costs of living or raising an Autistic person in Irish society. This research highlighted that costs can be as high as €28,464.89 per year.²⁷ This chimes with the *Department of Social Protection and Indecon Report on the Cost of Disability in Ireland*, which established the significant additional cost of living that many Disabled people and 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.²⁸

²⁶ Centre for Inclusive Policy, 'Disability Policy Insights Rethinking Disability Social Protection Policy - Policy Brief No.

^{1&#}x27;, https://inclusive-policy.org/wp-content/uploads/2025/05/Policy-Brief-1_FINAL2.pdf (accessed 25 Jun 2025).

²⁷ 10 C. O'Neill, Á. Roddy 'The Economic Costs and Its Predictors for Childhood Autism Spectrum Disorders in Ireland: How Is the Burden Distributed?',

https://journals.sagepub.com/doi/full/10.1177/1362361318801586 (accessed 26 Jun 2025)

²⁸ Indecon, 'Cost of Disability Report', p.14, https://assets.gov.ie/static/documents/the-cost-of-disability-in-ireland-research-report.pdf (accessed 25 Jun 2025).

The report also estimates that the average additional costs of living as a Disabled person in Irish society were around €11,734 per year. This included unmet needs of between €2,522 and €3,821 per year arising from having to pay for additional expenses related to their disability.²⁹

More concerningly, a recent Report from the Irish Human Rights and Equality

Commission and the ESRI suggests that Ireland significantly underestimates the scale of poverty and social exclusion experienced by households with Autistic or Disabled people.

The Report asserts that Ireland underestimates the extent that additional disabilityrelated costs can dramatically reduce the income and living standards of Autistic and
Disabled people and families. Such financial pressures restrict their autonomy, decisionmaking capacity and opportunities to realise their rights under the UNCRPD. The Report
highlighted that households with a Disabled family member need an income increase of
between 52% and 59% to achieve the same standard of living as households with a
non-Disabled family member. Coupled with inflation, additional costs related to disability
ranged between €488 and €555 per week (€25,376-€28,860 per year), significantly
higher than the Indecon *Cost of Disability* Report.³⁰ Moreover, it also states that for
households with a family member with high support needs, they would need an income
increase of 93% to achieve this same standard of living.³¹

This reflects the *Roadmap's* key shortcoming - its failure to substantively address disability poverty and the additional costs of disability, which greatly affect Disabled people and families' quality of life and living standards. To illustrate this, a recent ESRI Report asserts that having a Disabled household member is a contributing factor to a

²⁹ Indecon, 'The Cost of Disability in Ireland', https://assets.gov.ie/static/documents/the-cost-of-disability-in-ireland-research-report.pdf (accessed 26 Jun 2025)

³⁰ Economic and Social Research Institute, 'Adjusting Estimates of Poverty for the Cost of Disability', https://www.ihrec.ie/app/uploads/2025/03/Adjusting-Estimates-of-Poverty-for-the-Cost-of-Disability.pdf (accessed 26 Jun 2025)

³¹ Economic and Social Research Institute, 'Adjusting Estimates of Poverty for the Cost of Disability', https://www.ihrec.ie//app/uploads/2025/03/Adjusting-Estimates-of-Poverty-for-the-Cost-of-Disability.pdf (accessed 26 Jun 2025)

family experiencing poverty, and regardless of their income, they³² Moreover, the scale of unmet access needs highlights the critical need for action from the Department - including the introduction of a Cost of Disability payment and the future benchmarking of social protection payments. This also means taking a comprehensive, whole-of-Government approach to addressing barriers to public services which support the Disabled and Autistic communities like healthcare, disability supports, mental health, personal assistance, transport, housing and employment. We also call on the Department of Social Protection to collaborate with the HSE to formally introduce a Personalised Budget Scheme that supports with both meeting these costs and addressing barriers previously mentioned, without this affecting their access to disability social welfare payments and other supports they access, including Free Travel or the Medical Card.

³² Economic and Social Research Institute, 'Deprived children in Ireland: Characterising those who are deprived but not income-poor', https://www.esri.ie/system/files/publications/RS217.pdf accessed 27 Jun 2025.

Community Experiences in Dealing with the Department and Employment Services

Autistic people often engage with both the Department of Social Protection and with Intreo to access social protection payments such as Jobseekers Allowance, Illness Benefit, and access Intreo schemes, which support people seeking work into employment and further education and training. Community members have identified their experiences in dealing with Intreo as a key issue that affects their experiences with finding work and with navigating the social protection system. Some testimonies community members shared with us include:

"The forms required for DA [Disability Allowance] are long and difficult to understand at times. The process is exhausting to complete and requires a lot of additional documentation that is difficult to obtain and gather. They need to provide a more accessible route to access. Additionally, all staff at Intreo centres should be trained in autism awareness/there should be dedicated support agents for those with disabilities."

"The forms and process are difficult to understand primarily, and when not approved for anything financial, no other assistance was offered to me. I had to be proactive and call down to Intreo to ask what I can do with all of my free time because I have been trying to find a full time PRSI job for 2 years now... it is still a slog and I have trouble interviewing in particular, despite several attempts and I have taken all available courses."

This speaks to the need for Universal Design to be at the core of the Department of Social Protection, particularly with respect to making application processes, environments and personal supports more accessible.

Inconsistencies in Disability Assessments and their Impact in Accessing Disability Supports

AsIAm finds that the Department of Social Protection's current approach to disability assessments frequently results in inconsistencies when determining who qualifies for benefits or supports. Eligibility for disability-related social protection payments frequently hinges on the 'functioning label' assigned to an Autistic person, which are often applied without meaningful input from the individual or a full understanding of their lived experiences.

AsIAm's engagement with the Autistic community reveals that many Autistic people and families find the process of applying for and accessing social protection payments to be deeply intrusive and distressing. A significant concern is the burden placed on applicants to prove the extent to which their disability or neurodivergence affects their everyday lives to qualify for support.

Community members have shared stories with us of feeling upset, humiliated or distressed throughout the application and appeals process. Many felt that they were not treated with dignity, but with suspicion at every stage. Community members also described how being required to disclose deeply sensitive personal information or recount traumatic experiences to show eligibility was retraumatising, making an already difficult process even more stressful.

It seems clear from community members' experiences that applying for disabilityrelated welfare supports causes significant anxiety and hardship. Many Autistic people
and families tell us that they feel demonised by a system that should instead support
and empower them. The current assessment process also does not factor in many
Autistic people's differences and support needs, including communication differences,
and differences in sensory processing and in processing information, which we highlight
in our <u>Guide for Newly Diagnosed Autistic Adults</u>. As a result, many Autistic applicants
and families struggle to meet the Department's expectations and requirements, which
are often not accommodated to meet their access needs.

This approach fails to consider evolving attitudes towards Disability and neurodiversity following Ireland's ratification of the UNCRPD. This does not comply with Article 28 of the UNCRPD, and as a result, many Autistic and Disabled people are excluded from support because their access needs fall outside rigid 'functioning labels' which may not reflect their everyday lived experiences.

The European Disability Forum (EDF) underscores these concerns in its Report on social protection across the European Union. The Report highlights how disability assessments based off the medical model used by many EU member states' social protection policies and systems – including Ireland – often do not accurately assess a person's real support needs. The EDF states:

"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"³³

³³ European Disability Forum, Social Protection and the Welfare State: What the EU can do to Support Persons with Disabilities, 2022, p. 12.

Experiences and Barriers to Employment for Autistic People

AsIAm engages with community members on issues related to employment and social protection. Insights captured from our Same Chance Report provide a mixed picture - some community members are working part-time (11%), full-time (22%), not currently working (17%) or actively looking for work (5%).³⁴ Concerningly, 70% of people indicated that they were accessing no supports or accommodations in the workplace.³⁵

Community members highlighted several reasons why they had negative experiences of employment, such as:

- Fear of losing key welfare supports such as Free Travel and their Medical Card;
- Managing one or more co-occurring Disabilities, Conditions or Illnesses;
- Barriers in the recruitment process, such as job applications, interviews, and assessments;
- Lack of jobs available that match their skills, interests and qualifications;
- Lack of suitable or accessible jobs in their locality;
- Recovering from illness or burnout, or with mental health difficulties;
- Experiences of discrimination, ill-treatment, or lack of supports in the workplace;
- Fear of negative consequences after disclosing that they are Autistic;
- Barriers to accessing career development or progression opportunities as Neurotypical colleagues.

The Department highlighted that many of these issues were shared across the Disabled community in the *Roadmap for Social Inclusion*³⁶. In the *Roadmap*, the Department highlighted that for many Disabled people, starting a new job often involves navigating a complex web of rules to determine what supports they can keep. This can force

³⁴ AslAm, Same Chance Report 2025, p.44, https://cdn.prod.website-

files.com/6537ebfefba7b3c24a18e646/67e572276f39ff1d6d830135_Version%203%20Digital%20Full%20AsIAm%20 Same%20Chance%20Report.pdf (accessed 26 Jun 2025).

³⁵ AsIAm Same Chance Report 2025, https://cdn.prod.website-

<u>files.com/6537ebfefba7b3c24a18e646/67e572276f39ff1d6d830135_Version%203%20Digital%20Full%20AsIAm%20Same%20Chance%20Report.pdf</u> (accessed 26 Jun 2025)

³⁶ Department of Social Protection, 'Roadmap for Social Inclusion 2020 - 2025 Ambition, Goals, Commitments', p. 56 https://assets.gov.ie/static/documents/roadmap-for-social-inclusion-2020-2025-ambition-goals-commitments.pdf (accessed 26 Jun 2025)

individuals to weigh the benefits of employment against the potential loss of vital supports they need.³⁷ In our *Autism in the Workplace* Report, 84% of respondents said that they do not feel confident that employers, managers, colleagues and clients know enough about autism to support them at work³⁸. We also found that 60% of all autistic people do not believe or are unsure about whether they have the same chance of career progression as non-autistic employees.³⁹

More starkly, the Report also found that 85% of Autistic adults are unemployed or underemployed. Autism Europe suggests that the employment rate of Autistic people may be as low as 5-15%. This has far-reaching implications on Autistic people's well-being, connectedness and sense of identity. These experiences also underscore the interconnectedness between poverty, material deprivation, mental and physical health, and Autistic adults' self-worth and ability to live independently and participate fully in society.

In our Submission to the Department of Social Protection on Disability Income Supports Reform, we observed:

"barriers in society have created a climate of 'low expectations,' that many
Autistic people and Disabled people experience. Many Autistic people and
Disabled people experience low confidence and self-esteem because of a lack
of opportunities, from experience of a lot of rejection and adversity in life and

³⁷ Department of Social Protection, 'Roadmap for Social Inclusion 2020 - 2025 Ambition, Goals, Commitments', p. 56 https://assets.gov.ie/static/documents/roadmap-for-social-inclusion-2020-2025-ambition-goals-commitments.pdf (accessed 26 Jun 2025)

³⁸ AsIAm, Autism in the Workplace, https://cdn.prod.website-

files.com/6537ebfefba7b3c24a18e646/65f201020206226bbd209458_Autism-in-the-Workplace-Report-New-Logo.pdf accessed 26 Jun 2025.

³⁹ AslAm, Autism in the Workplace, https://cdn.prod.website-files.com/6537ebfefba7b3c24a18e646/65f201020206226bbd209458_Autism-in-the-Workplace-Report-New-Logo.pdf accessed 26 Jun 2025.

⁴⁰ AslAm, 'Autism in the Workplace Report', https://cdn.prod.website-files.com/6537ebfefba7b3c24a18e646/65f201020206226bbd209458_Autism-in-the-Workplace-Report-New-Logo.pdf (accessed 26 Jun 2025)

⁴¹ Autism Europe, 'Bridging the Autism Employment Gap in Europe: A Compendium of Current Practices and Initiatives', p. 3, https://www.autismeurope.org/wp-content/uploads/2023/10/ENG_INFUSE-Compendium-of-best-practices.pdf (accessed 26 Jun 2025)

from not having the same chance to be accepted and included in Irish society, from inaccessible or exclusionary workplaces or working practices."⁴²

Autistic peoples' experiences within the workplace also deeply affect their wellbeing, identity and sense of belonging. When in the right job with the right supports, many Autistic people held positive attitudes towards employment, providing dignity, identity, financial independence and purpose. However, Autistic adults' experiences show that this was not typically the case, and Autistic employees often felt pressure to 'mask' or adapt their ways of being or processing the world to meet their employer's expectations. They also felt that this flexibility is often not reciprocated by employers. Many Autistic people reported feeling unsafe to be open about their diagnosis or Autistic identity, fearing it would be used against them or their request for supports would be denied.

Some Autistic people shared that they had requests for reasonable accommodations during job interviews - such as receiving interview questions in advance - were refused. They were told by prospective employers that they "have to treat everyone equally", or were dismissed because they did not "look" or "seem" Autistic enough to justify the employer putting the support in place. Others worried that disclosure would lead to being held to higher standards or treated differently or unfairly.

These experiences show that Autistic adults often deliberate on whether to disclose that they are Autistic at work, and they do not take the decision to disclose or talk about their access needs lightly. Many Autistic people believe that autism continues to be misunderstood and stigmatised by employers who hold medicalised attitudes about autism. As a result, they may not feel safe or supported in revealing their diagnosis, fearing discrimination or exclusion, and understandably, many Autistic adults feel

⁴² AslAm, 'AslAm Submission to the Department of Social Protection on Disability Income Supports Reform', p.49, https://cdn.prod.website-

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reluctant to have that conversation with an employer or feel that their experiences would be believed.

This highlights that many Autistic adults feel that employers' would not understand what it means to be Autistic, and why accommodations are needed to meet their needs. This further discourages disclosure and access to vital supports or accommodations.

In our most recent 'Autism in the Workplace' Report, 96% of Autistic adults felt they would find it more difficult to find the job they want compared with a Neurotypical person, whilst 51% of Autistic adults say that they find current supports and reasonable accommodations from their employer are insufficient to meet their needs. We also highlight that just 20% of Autistic people had requested a Reasonable Accommodation from an employer, and 58% of Autistic people believed that requesting Reasonable Accommodation would hinder their prospects of securing their preferred role. However, with the right supports, 94% of Autistic people believe that they would be an asset to any business or organisation. At 82% of Autistic adults in employment also said being autistic gives them specific strengths in their current role. The burden on the person to research available supports and having to seek prior approval from the employer can act as a deterrent, discouraging them from accessing the accommodations they need. For these reasons, the Department should offer greater support to Autistic and Disabled applicants during the recruitment process.

⁴³ AslAm, 'Autism in the Workplace', https://cdn.prod.website-

 $[\]frac{\text{files.com}/6537\text{ebfefba7b3c24a18e646}/65f201020206226bbd209458_Autism-in-the-Workplace-Report-New-Logo.pdf} \text{ (accessed 26 Jun 2025)}$

⁴⁴ AslAm, 'Autism in the Workplace', https://cdn.prod.website-files.com/6537ebfefba7b3c24a18e646/65f201020206226bbd209458_Autism-in-the-Workplace-Report-New-Logo.pdf (accessed 26 Jun 2025)

Public Attitudes and the Role of Social Protection

A key challenge for the Department for the next Roadmap is to address the pervasive negative stereotypes associated with receiving social protection payments, and wider public attitudes on the role of social protection as a 'social safety net'. Many Autistic people who are not in employment but are deemed 'fit to work' may not qualify for Disability Allowance, and instead receive Jobseekers payments, even though they still experience significant structural barriers when engaging with employment services. For example, some Autistic people feel pressured to take work or enrol in training courses to retain their payment, whilst others also find the process of applying for supports arduous, complex and difficult to navigate. In our submission on the Green Paper, we highlighted that the assessment process is out-of-step with a rights-based, neuro-affirmative approach set out by Article 28 of the UNCRPD. The rigidity of this system leaves many people who want to work with little or no access to support.

It should be noted that levels of autism acceptance and understanding in society continue to pose significant barriers to Autistic people accessing meaningful employment opportunities. In our Same Chance Report 2025⁴⁵, we provided a representative sample of the Irish public with a series of vignettes describing common experiences of Autistic people in the community, without explicitly stating the case studies involved an Autistic person. When presented with the story of "Ben" - a young Autistic man seeking employment in a retail environment – 2 in 5 of the Irish public found basic accommodations such as communication preferences and working times as "unreasonable" whilst 39% said they would be unlikely to hire Ben having heard a description of his communication differences at interview. It is critically important to improve public attitudes to Autism in order to enable more Autistic people to access and thrive in the workplace.

⁴⁵ AslAm, 'Annual Same Chance Report and Attitudes to Autism Poll 2025', p. 55-60, https://cdn.prod.website-files.com/6537ebfefba7b3c24a18e646/67e572276f39ff1d6d830135_Version%203%20Digital%20Full%20AslAm%20Same%20Chance%20Report.pdf (accessed 27 Jun 2025).

We believe that the Department of Social Protection should take a neuro-affirmative approach to disability assessment – which recognises the Autistic community's diversity of needs and ensures fair, inclusive access to payments and supports.

Independent Living and Access to Housing

A key issue Autistic people and families experience which is highlighted in the Roadmap for Social Inclusion highlights access to housing and the right to live independently in the community. Article 19 of the UNCRPD promotes the philosophy of Independent Living, which focuses on people having choice, control and capacity to make decisions over their lives, building community and connectedness, and using Independent Living to unlock other rights, including employment, transport and participation in the community. 46, our *Same Chance Report* highlighted several barriers Autistic people and our wider community face in accessing housing supports, including:

- 71% of those surveyed noted they do not believe they have access to enough supports to live independently in the community;
- 33% of respondents surveyed said their current housing situation did meet their needs;
- 48% do not feel safe and protected in their community;

Promoting Autistic People's Wellbeing and Tackling the Effects of Isolation and Social Exclusion

For many Autistic people and families, feeling accepted and supported to fully participate in their community and society is more than just addressing poverty, but also requires addressing the wider barriers to acceptance, community inclusion and participation that shape their daily lives. Through our engagement with Autistic people and families across Ireland, we observe the isolating impact of not having access to essential services and supports, such as accessible housing, public transport, inclusive public environments and services, independent living supports such as personalised budgets and Personal Assistance services. These supports are vital for many Autistic people to achieving wellbeing and effectively tackle social exclusion within our

⁴⁶ Independent Living Movement Ireland, 'What Is Independent Living', https://ilmi.ie/what-is-independent-living/ accessed 26 Jun 2025.

community. A recent survey of our community members show the extent of this social exclusion:

- 55% of Autistic adults felt lonely all or most of the time;
- 34% felt lonely some of the time;
- 40% lived with at home with their parents;
- 18% had not been out socially in over 6 months;
- 17% had not taken part in any social events in the last 12 months;
- 69% of Autistic adults felt left out of society;
- 63% of respondents said that there were no activities in their area that matched their interests;
- 34% said that a family member who they live with was their primary source of social interaction;
- 87% of respondents said that being Autistic is a barrier to forming friendships;
- 95% of respondents believe that being Autistic was a driving force to feeling lonely;

These findings reflect that many Autistic adults do not have the opportunity to enjoy key component of Article 19 of the UNCRPD – being included and feeling like they belong and are part of their wider community. Many daily activities that foster connection and support – such as socialising, accessing local services or amenities, or engaging in leisure activities – remain inaccessible to Autistic people. This often arises from a lack of choice, autonomy, or not having support services they want

Programme for Government Commitments on Disability and Social Protection

The *Programme for Government*, published in January 2025, includes several welcome commitments around social protection, including a pledge to fully abolish the means test for Carers Allowance. This has been a long-standing call of AslAm and other organisations within the disability sector. Family Carers Ireland estimate that carers contribute over €20 billion in value annually to the State.⁴⁷ Recognising and meaningfully supporting their vital work through such actions is a significant step forward.

Other key commitments by the Government include:

- Introduce a permanent annual Cost of Disability Payment, with plans to incrementally increase 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.

⁴⁷ Family Carers Ireland, https://www.familycarers.ie/about-us/family-caring-in-ireland/caring-by-numbers (accessed 26 Jun 2025.)

 Promote training initiatives to raise awareness and the understanding of disabilities amongst Intreo staff.

Commitments under the Autism Innovation Strategy

In 2024, the Government introduced the <u>Autism Innovation Strategy</u> to coordinate actions aimed at improving access to services and supports for Autistic people and families. The Strategy, which spans 18 months, includes 83 actions - five of which fall under the remit of the Department of Social Protection:

1. Support for Citizens Information Services and Advocacy:

Staff in Citizens Information Board-funded organisations will be supported to engage with a new public sector e-learning module on disability equality. This training will include content specific to the needs of Autistic people.

2. Accessible MyWelfare Applications:

To ensure the accessibility and user-friendliness of MyWelfare applications, the Department will consult with Autistic users and other Disabled individuals as part of the process of digitalising applications for disability schemes.

3. Up-to-Date Information on Services and Supports:

The Department will ensure that accurate and relevant information for Autistic people is provided through *citizensinformation.ie* and the *Guide to Entitlements* for People with Disabilities. This will include links to services and supports such as assistive technology, hosted on other public sector sites.

4. Review of Disability Awareness Training at Intreo:

Disability awareness training for Intreo (the Public Employment Service) staff will be reviewed to ensure staff are well-equipped to support employment opportunities and address challenges for Disabled people, including Autistic individuals.

5. **Sensory-Friendly Intreo Environments**:

A quiet room will be available in every Intreo office by the end of the first quarter of 2025, to provide a supportive environment for Autistic people and those with sensory processing differences.

Although these commitments are welcome, the Department must not only meet these goals but also build on them in the next Roadmap. It will be essential to address the

structural barriers that limit Autistic people's access to social protection and perpetuate social exclusion - issues which are reflected in the following recommendations.

Recommendations for the Next Roadmap for Social Inclusion

AsIAm proposes the following recommendations for the Department of Social Protection to include in the successor to the *Roadmap for Social Inclusion* and in the development of future social protection policies:

Income Supports and Financial Security

- Abolish means testing for key disability welfare payments, including Carer's Allowance and Disability Allowance.
- Introduce a universal Cost of Disability Payment that is not means-tested and addresses the additional costs of disability.
- Increase the Carers Support Grant and standardise the age transition between Domiciliary Care Allowance (DCA) and Disability Allowance from 16 to 18, ensuring a 'no-loss' basis by providing a higher DCA rate for children aged 16–17.
- Raise core social protection payments (Disability Allowance, DCA, and Carers Allowance) in line with inflation, cost of living, and wage growth.
- Provide a monthly payment to families accessing the Access and Inclusion
 Model (AIM) (Level 7).
- Although the main responsibility of the Revenue Commissioners, we are calling
 for increases to the "Incapacitated Child" Tax Credit and to rename the Credit
 to align with a rights-based, neuro-affirmative approach to social protection.
- Introduce a Personalised Budget Scheme in partnership with the HSE to
 provide Autistic and Disabled people with more control, autonomy and flexibility
 over the supports and services they access, promoting more choice in how they
 wish to meet their individual support needs and engage with service providers.

Promoting Equality-Proofing Services and Inclusive Policy Development

- Implement a holistic approach to equality-proofing and disability-proofing all new and existing payments to prevent disproportionate impacts on marginalised groups, including Autistic people, family carers, and lone parents.
- Accept a wider range of evidence of disability in applications, recognising unequal access to assessments and diagnosis pathways.

Expanding Employment Supports and Reasonable Accommodations

- Reform the Work and Access Scheme:
 - o Reduce minimum required working hours to 10 per week.
 - o Redirect payments directly to employees rather than employers.
 - o Actively promote the scheme to encourage hiring of Autistic people.
- Provide in-person and application support for Disabled and Autistic applicants navigating work-related schemes.
- Support organisations, including Disabled Persons Organisations (DPOs) and community and voluntary sector organisations to assist Autistic and Disabled jobseekers accessing employment.

Building Accessible and Inclusive Workplaces

- Mandate Autism Understanding and Disability Equality Training for all Intreo and Department of Social Protection staff.
- Ensure universal design is incorporated across all Intreo offices, services, and application processes.
- Require employers to:
 - Engage with employment services for Disabled people.
 - o Make reasonable accommodations.
 - o Complete Autism training.

- o Implement **disability hiring quotas**, beginning with state agencies in line with the public sector hiring quota and expanding to the private sector in partnership with the Department of Enterprise, Trade and Employment.
- Create a central portal for employers and employees highlighting available workplace accommodations and supports.

Reforming Disability Assessments and Access to Supports

- Significantly reduce **waiting times for disability assessments** and limit unnecessary reassessments that place undue stress on applicants.
- Take a neuro-affirmative and person-centred approach to disability assessments, considering:
 - o The full diversity of Autistic lived experience.
 - o Communication and sensory processing differences.
 - o Variations in support needs across time and context.
- Design assessments and applications to prioritise the dignity, agency, and preferences of the applicant, consistent with Universal Design Principles.
- Provide Access Officers or similar roles to support Autistic and Disabled applicants in identifying and securing appropriate supports.

Rights-Based Implementation

- Avoid placing the burden of proof for eligibility solely on Autistic or Disabled people. The system should aim to meet a person's support needs rather than question the validity of their diagnosis or support needs.
- Reimburse applicants for out-of-pocket expenses related to acquiring accommodations (e.g., medical letters, clinical appointments).
- Engage in a cross-departmental review of the Government's 6% hiring quota
 for Disabled people across the public sector, increase this to reflect the growth
 of the disability population in <u>Census 2022</u>. Gradually introduce similar targets
 across the private sector and support the Community and Voluntary sector to
 recruit more Autistic and Disabled people.