

AsIAm Submission to the United Nations Committee on Rights of Persons with Disabilities

For consideration when compiling the List of issues on the First Periodic Report of Ireland

under the Convention on the Rights of Persons with Disabilities.

15th July 2025.

AsIAm, Ireland's Autism Charity, welcomes the opportunity to send a submission to the United Nations Committee on the Rights of Persons with Disabilities (known thereafter as the UN CRPD Committee) to support their compilation of a 'List of Issues' (LOI) which they will raise with the Government of Ireland during their appearance before the Committee. In light of both recent issues that affect our community and barriers affecting the wider Disabled community, AsIAm see this as timely opportunity to inform the UN CRPD Committee about issues of concern with respect to Ireland's ratification of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), and highlight barriers faced by Autistic people and Disabled people in realising their rights.

For this submission, AsIAm have focused on a number of issues covered in the List of Issues impacting our community which we would recommend the UNCRPD Committee focus on when drawing up their List of Issues for Ireland: (Article 4) Children with Disabilities (Article 7), Awareness Raising (Article 8), Access to Justice (Article 13), Liberty and Security of the

Person (Article 14), Freedom from torture or cruel, inhuman or degrading treatment (Article 15), Living independently and being included in the community (Article 19), Education (Article 24), Health (Article 25), Work and Employment (Article 27), Adequate standard of living and social protection (Article 28), and statistics and data collection (Article 31).

#### **About AsIAm**

AsIAm is Ireland's Autism Charity. Founded in 2014, AsIAm advocates for an inclusive society for Autistic people that is accessible, accepting and affirming. We work to support the Autistic community and our families throughout the lifecycle to fully engage in Irish life and build the capacity of society to facilitate true inclusion. This is achieved through the programmes of support we offer and our advocacy work. AsIAm provides a range of programmes through our national and regional based activities and programmes.

AsIAm is a Disabled Person's Organisation (DPO) as we are Autistic led, informed by the experiences of Autistic people, and more than half of our staff and board are Autistic or have other differences or disabilities. AsIAm's work focuses on advancing the rights of Autistic people across Irish society. We use a rights-based, Neuro-affirmative approach in all our work supporting Autistic people across all supports within the organisation. AsIAm is also a founding member of the DPO Network - an alliance of five national DPOs who collectively advocate for the rights of Disabled people and to advance the full implementation of the UNCRPD in Ireland, across all our laws and policies.

#### **About Autism**

Autism is a lifelong developmental difference or disability which relates to how a person communicates and interacts with others and how they experience the world around them. In keeping with our community's preferences, AsIAm uses identity-first language ("i.e. Autistic person") throughout this submission to reflect that their experience of autism is a core part of their identity and central to their experience of living in Irish society. Further details about Autistic people's language preferences can be found in our Language Guide <a href="here">here</a>.

#### Introduction

AsIAm welcomes recent measures taken by the Government to promote the rights of Autistic and Disabled people, particularly following Ireland's submission of its Initial Report to the United Nations Committee on the Rights of Persons with Disabilities. Positive developments include Ireland's accession to the Optional Protocol of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), the development of the *National Housing Strategy for Disabled People 2022–2027*<sup>1</sup>, and the *Comprehensive Employment Strategy for People with Disabilities 2015–2024 (CES)*<sup>2</sup>, and the *Autism Innovation Strategy (2024)*<sup>3</sup> as well as a successor to the National Disability Strategy.

However, we are concerned that Ireland is becoming a "policy-rich, implementation-poor" country<sup>4</sup>. Despite legal protections and targeted supports, many of the UNCRPD's general obligations and specific rights remain unfulfilled in practice. Disabled and Autistic people continue to face disproportionately high rates of poverty, social exclusion, unemployment, segregation from mainstream education, and structural discrimination – much more so than the general population.

A key challenge to effective UNCRPD implementation in Ireland is the lack of robust systems to monitor the execution of policies affecting marginalised communities, including Autistic

<sup>&</sup>lt;sup>1</sup> Department of Housing, Local Government and Heritage, 'National Housing Strategy for Disabled People 2022 – 2027', <a href="https://www.housingagency.ie/sites/default/files/2023-08/National-Housing-Strategy-for-Disabled-People-2022-2027.pdf">https://www.housingagency.ie/sites/default/files/2023-08/National-Housing-Strategy-for-Disabled-People-2022-2027.pdf</a> (accessed 07 Jul 2025).

<sup>&</sup>lt;sup>2</sup> Government of Ireland, 'Comprehensive Employment Strategy for People with Disabilities 2015-2024', https://assets.gov.ie/18906/1120bc6ad254489db9571c74e8572f44.pdf (accessed 07 Jul 2025)

<sup>&</sup>lt;sup>3</sup> Government Of Ireland, 'Autism Innovation Strategy' <a href="https://assets.gov.ie/static/documents/autism-innovation-strategy-august-2024.pdf">https://assets.gov.ie/static/documents/autism-innovation-strategy-august-2024.pdf</a>

<sup>&</sup>lt;sup>4</sup> European Anti-Poverty Network Ireland, 'Delivering Change and Achieving Ambition: Progress on the Roadmap for Social Inclusion 2020-2025', <a href="https://eapn.ie/wp-content/uploads/2024/06/Social-Inclusion-Forum-2024-EAPN-Ireland-and-CWI-Preparatory-Workshops-Report.pdf">https://eapn.ie/wp-content/uploads/2024/06/Social-Inclusion-Forum-2024-EAPN-Ireland-and-CWI-Preparatory-Workshops-Report.pdf</a> (accessed 07 Jul 2025.)

people. Additionally, there is a notable absence of disaggregated data, which is critical to identifying and addressing the specific needs of our community. Furthermore, there is insufficient recognition of Disabled Persons' Organisations (DPOs) and a lack of adequate support to ensure their meaningful involvement in both the implementation and monitoring of the CRPD.

**Article 4: General Obligations** 

Issues: Meaningful Engagement and Co-Creation with Disabled Persons

Ireland's State Report to the UN CRPD Committee notes that the Government funded the

development of the Disability Participation and Consultation Network (DPCN) to "build

capacity within the disability community so that people with disabilities, their representative

organisations and disability organisations can participate fully in the development of policy

and legislation as required under the Convention."5 Article 4.3 of the UNCRPD, along with

General Comment 7, clearly states that countries like Ireland must ensure meaningful

engagement and co-creation with Disabled Persons' Organisations (DPOs) in the design,

implementation, delivery, and review of policies that affect them and their communities.<sup>6</sup>

However, a 2023 evaluation of the DPCN conducted by the National Disability Authority found

that the Network did not align with the UNCRPD, citing issues related to funding, reporting,

and structural barriers to participation between members.<sup>7</sup>

As highlighted earlier, AsIAm is a founding member of the DPO Network. Like many DPOs,

AsIAm requires multi-annual funding to ensure it has the capacity to effectively represent

Autistic people, contribute meaningfully to policy development, monitor UNCRPD

<sup>5</sup> Central Statistics Office, 2024 Survey on Income and Living Conditions,

 $\underline{\text{https://www.cso.ie/en/releases} and \underline{\text{publications/ep/p-silc/surveyonincome} and \underline{\text{livingconditionssilc2024/keyfindings/p-silc/surveyonincome} and \underline{\text{livingconditionssilc2024/keyfindings/p-silc/surve$ 

(accessed 26 Jun 2025).

<sup>6</sup> General Comment 7. See Committee on the Rights of Persons with Disabilities (2018), General Comment No. 7

(CRPD/C/GC/7). (accessed 07 Jul 2025).

<sup>7</sup> National Disability Authority, 'Independent Evaluation of the Disability Participation and Consultation Network - December 2023', <a href="https://nda.ie/uploads/publications/Independent-Evaluation-of-the-Disability-Participation-and-Consultation-Network-December-2023-final.pdf">https://nda.ie/uploads/publications/Independent-Evaluation-of-the-Disability-Participation-and-Consultation-Network-December-2023-final.pdf</a> (accessed 07 Jul 2025.)

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implementation at both local and national levels, and meet growing demands for engagement and co-creation from Government and statutory bodies.

To meet these obligations, DPOs must also be granted access to the resources necessary for community capacity-building and training Disabled people to engage fully in these processes. Meaningful engagement and co-production benefit all parties—DPOs, their communities, and the Government—by ensuring that policies are responsive to Disabled peoples lived experiences, address structural barriers, and empower Disabled people to realise their rights as full and equal citizens. Budget allocations should reflect this by supporting DPOs to participate fully and sustainably in policy processes, in line with Ireland's obligations under the UNCRPD.

Furthermore, Government departments and State agencies must ensure their engagement processes are accessible, inclusive, and structured to facilitate DPOs to support their representatives to contribute their lived experience and expertise. They must also have the internal capacity, understanding, and systems to meaningfully and sustainably support this collaborative policymaking and development. AsIAm's experience with different government departments and agencies has varied under this obligation, with some Departments more willing to engage with us than others.

Our experience in working with Government departments and State agencies provides a mixed picture in terms of engagement – although some Government departments (including the Department of Children, Disability and Equality) have shown a willingness to engage with DPOs in policy development, others have shown more reluctance to directly engage with DPOs. In several instances, important policy decisions have been made with little to no consultation with AsIAm, other DPOs, or representative organisations. This lack of

engagement has caused significant anxiety among many Autistic people and our wider community and has had a detrimental impact on their wellbeing and their ability to exercise rights under the UNCRPD.

# The Public Sector Equality and Human Rights Duty

The introduction of the Public Sector Equality and Human Rights Duty places a legal obligation on public bodies and local authorities to promote equality and human rights across all areas of their work. This duty holds significant potential to shape how the UNCRPD is implemented at both local and national levels - particularly in our education system, workplaces, public buildings, and access to services and supports. If meaningfully applied, it could transform the lives of Autistic people by making supports more accessible and by ensuring that their rights are recognised and upheld.

The reality for many of our community members is that they still experience structural barriers to accessing public services, particularly within their local community. Many describe current systems for accessing public services as confusing and difficult to navigate, with lack of access itself being one of the main barriers to full participation and social inclusion in society.

Compounding this issue is the inconsistency across Irish legislation in how disability is defined.

The Disability Act 2005<sup>9</sup>, the Equal Status Act 2000<sup>10</sup>, and the Employment Equality Acts<sup>11</sup>

<sup>8</sup> Section 42, 'Irish Human Rights and Equality Commission Act 2014', https://www.irishstatutebook.ie/eli/2014/act/25/section/42/enacted/en/html (accessed 07 Jul 2025)

<sup>&</sup>lt;sup>9</sup> Disability Act 2005, <a href="https://www.irishstatutebook.ie/eli/2005/act/14/enacted/en/html">https://www.irishstatutebook.ie/eli/2005/act/14/enacted/en/html</a> (accessed 07 Jul 2025).

<sup>&</sup>lt;sup>10</sup> Equal Status Act 2000, https://www.irishstatutebook.ie/eli/2000/act/8/enacted/en/html (accessed 07 Jul 2025).

<sup>&</sup>lt;sup>11</sup> Employment Equality Acts 1998-2015, <a href="https://revisedacts.lawreform.ie/eli/1998/act/21/front/revised/en/html">https://revisedacts.lawreform.ie/eli/1998/act/21/front/revised/en/html</a> (accessed 07 Jul 2025).

each use different definitions of disability, none of which comply with the UNCRPD. These definitions are largely rooted in a Medical Model or deficit-based understanding of disability, which fails to reflect a Social Model or Neurodiversity-affirming approach. The latter considers the impact of social and environmental barriers that disable individuals from participating fully and equally in society.

Furthermore, these legal definitions often categorise autism as a 'disorder,'12 using negative and pathologising language that does not reflect the lived experiences of Autistic people. This includes the use of functioning labels such as "high-functioning" or "low-functioning," which reinforce negative stereotypes about autism. Such language implies that Autistic traits need to be treated or cured, rather than understood and supported through inclusive, neuro-affirmative approaches that promote acceptance, participation, and wellbeing.

There is a growing body of policy and research which highlights what neuro-affirmative practices look like, where both the State and policymakers can support both Autistic people and Neurodivergent people sensitively and which respects their fundamental rights and freedoms – including to live in society as they are.<sup>13</sup> Key principles of neuro-affirmative approaches include:

 Recognise Autistic peoples' experiences as a different way of experiencing and understanding the world, not a 'disorder' needing to be fixed or treated.

<sup>&</sup>lt;sup>12</sup> Section 7, Disability Act 2005. <a href="https://www.irishstatutebook.ie/eli/2005/act/14/enacted/en/print.html">https://www.irishstatutebook.ie/eli/2005/act/14/enacted/en/print.html</a> (accessed 07 Jul 2025.)

<sup>&</sup>lt;sup>13</sup> Hartman, D., O'Donnell-Killen, T., Doyle, J. K., Day, A., Kavanagh, M., Azevedo, J. 'What does it mean to be neurodiversity affirmative?', British Psychological Society, January 2024, What does it mean to be neurodiversity affirmative? | BPS (accessed 16 May 2024)

- Moving assessments and supports away from pathologising Autistic ways of being, toward promoting self-advocacy and a positive Autistic identity, with supports addressing access needs.
- Respecting Autistic culture and identity and meaningfully engaging with Autistic people to ensure that they are core to the design, delivery and monitoring og supports that meet their needs and vindicate their rights.
- Supporting the development of a positive Autistic identity, and advocating for changes to policies, practices, and attitudes to promote the rights of Autistic people.

#### **Suggested questions:**

- What actions are the Government taking to support Disabled Persons Organisations to facilitate their sustainable and meaningful engagement in consultation processes?
- How does the Government plan to meet its obligation to provide sustainable, multiannual funding to DPOs to make sure they have the structural and organisational capacity to co-produce policy and support the implementation of the UNCRPD in Ireland?
- What mechanisms does the State have in place to effectively monitor the implementation and impact of disability policies such as the new National Disability Policy, the Autism Innovation Strategy and the CRPD implementation Plan? What will the State do to make sure that these Strategies make meaningful improvements in the lives of Autistic people in Irish society?
- How does the State plan to build capacity of DPOs following the dissolution of the DPCN, and what avenues are available for DPOs to raise issues and hold Government

bodies and State agencies to account for meeting their obligation to actively engage with Disabled people on co-designing policies affecting their lives?

# **Specific Articles**

### Article 5: Equality and non-discrimination

### **Equality Acts**

Ireland is in the process of reviewing its Equality Acts, which commenced in 2021, but has not been completed. This delay in and of itself reflects a system that is not in keeping with its obligations to meet the needs of the Disabled community.

In recent years, attitudes towards disability and Autistic people have evolved. Increasingly, underrepresented **cohorts of our community**, including Autistic women and girls and LGBTQIA+ Autistic people, are accessing assessments, and diagnostic criteria are beginning to better reflect their lived experiences. However, Autistic people tell us that State services and supports are questioning the validity of their autism diagnoses, particularly when requesting access to accommodations or vital supports. This suspicion can be particularly pronounced where Autistic people may have different communication needs or preferences, including non-speaking members of our community.

Even more concerning is the growing prevalence of misinformation and stigma surrounding autism, which has contributed to an environment in which many Autistic people feel unsafe or uncomfortable to be themselves, to disclose they are autistic or requesting supports they

are entitled to. <sup>14</sup> Every year, AsIAm publishes our *Same Chance Report* which reflects the experiences of Autistic people and families in many aspects of Irish life. In this year's Report, we found that 92% of community members believe that misinformation about Autism and Autistic people has increased over the past year, and 91% of Autistic people feel that Irish society does not understand autism. <sup>15</sup> Considering the above, this reflects the need for Equality legislation to better reflect our community's living experiences and for the Equality Acts to be amended to be inclusive of both the growing diversity and intersectionality of our community.

#### **Reasonable Accommodations**

Disabled people in Ireland have a right to access reasonable accommodations under the Employment Equality Acts 1998-2015, unless these measures would impose a "disproportionate burden" on the Disabled person seeking supports. A reasonable accommodation is a "special treatment or facilities" which without which would be "impossible or unduly difficult for the person to avail himself or herself of the service" A duty bearer under this Acts is not obliged to provide reasonable accommodations if they amount to more than a "nominal cost" or if it would simply be difficult for a Disabled person to access goods and services. This is a lower standard than is set out in Article 2 of the UNCRPD,

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<sup>&</sup>lt;sup>14</sup> AsIAm, 'Same Chance Report', <a href="https://cdn.prod.website-">https://cdn.prod.website-</a>

files.com/6537ebfefba7b3c24a18e646/67e572276f39ff1d6d830135 Version%203%20Digital%20Full%20AsIAm%20Same% 20Chance%20Report.pdf (accessed 07 Jul 2025.)

<sup>&</sup>lt;sup>15</sup> AslAm, 'Same Chance Report 2025', https://cdn.prod.website-

files.com/6537ebfefba7b3c24a18e646/67e572276f39ff1d6d830135 Version%203%20Digital%20Full%20AsIAm%20Same% 20Chance%20Report.pdf (accessed 07 Jul 2025.)

<sup>&</sup>lt;sup>16</sup> Section 4, Equal Status Act 2000, <a href="https://www.irishstatutebook.ie/eli/2000/act/8/section/4/enacted/en/html">https://www.irishstatutebook.ie/eli/2000/act/8/section/4/enacted/en/html</a> (accessed 07 Jul 2025).

<sup>&</sup>lt;sup>17</sup> Section 4, Equal Status Act 2000, <a href="https://www.irishstatutebook.ie/eli/2000/act/8/section/4/enacted/en/html">https://www.irishstatutebook.ie/eli/2000/act/8/section/4/enacted/en/html</a> (accessed 07 Jul 2025).

which mandates the provision of reasonable accommodations to guarantee the full and equal enjoyment of all human rights and fundamental freedoms by Disabled people, unless they constitute a "disproportionate or undue burden".<sup>18</sup>

This discrepancy in standards makes it more difficult for Disabled people to access reasonable accommodations in employment, public services, and other areas where they may need supports to fully and equally enjoy their rights

## **Autism Innovation Strategy**

In 2024, the Department of Children, Equality, Disability, Integration and Youth introduced the *Autism Innovation Strategy*<sup>19</sup>, an 18-month Strategy comprising 83 actions, coordinated across Government departments and State agencies. The Strategy aims to address barriers identified by Autistic people and take concerted action towards building an autism-affirming society. Its core objectives include improving access to public services, developing accessible and inclusive communities, and building capacity within the Autistic community. The Strategy is grounded in principles that are "rights-focused, person-centred, neuro-affirmative, and delivered in the mainstream, where possible."<sup>20</sup>

<sup>&</sup>lt;sup>18</sup> Article 2, United Nations Convention on the Rights of Persons with Disabilities, <a href="https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-2-definitions.html">https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-2-definitions.html</a> (accessed 07 Jul 2025).

<sup>&</sup>lt;sup>19</sup> Department of Children, Equality, Disability, Integration and Youth, 'Autism Innovation Strategy', <a href="https://assets.gov.ie/static/documents/autism-innovation-strategy-august-2024.pdf">https://assets.gov.ie/static/documents/autism-innovation-strategy-august-2024.pdf</a> (accessed 07 Jul 2025.)

<sup>&</sup>lt;sup>20</sup> Department of Children, Equality, Disability, Integration and Youth, 'Autism Innovation Strategy', p.23 <a href="https://assets.gov.ie/static/documents/autism-innovation-strategy-august-2024.pdf">https://assets.gov.ie/static/documents/autism-innovation-strategy-august-2024.pdf</a> (accessed 07 Jul 2025).

This approach reflects a shift in disability policy since Ireland ratified the UN Convention on the Rights of Persons with Disabilities (UNCRPD) in 2018. It acknowledges that Autistic people reflect the diversity of Irish society, have a wide range of support needs related to being Autistic, and often face systemic barriers due to a lack of societal acceptance or understanding. <sup>21</sup>

Crucially, the Strategy also recognises the intersectionality within the Autistic community. It highlights the specific barriers faced by:

- Autistic adults;
- Non-speaking or minimally speaking individuals;
- Autistic women and girls;
- LGBTI+ members of the Autistic community;
- Autistic members of the Traveller and Roma communities;<sup>22</sup>

Many of the Strategy's 83 actions focus on ensuring meaningful consultation with Autistic people in the development of Government policies and public services. It also seeks to address longstanding gaps in autism-related research and policy, and to improve access to vital supports across health, social care, disability services, social protection, employment, and education—all of which directly affect the wellbeing of the Autistic community.

However, we are concerned that the Autism Innovation Strategy is not underpinned by legislation that commits the Government to regularly publishing a National Autism Strategy. Without a statutory basis, there is no guarantee that the progress achieved through this

<sup>&</sup>lt;sup>21</sup> Department of Children, Equality, Disability, Integration and Youth, 'Autism Innovation Strategy', <a href="https://assets.gov.ie/static/documents/autism-innovation-strategy-august-2024.pdf">https://assets.gov.ie/static/documents/autism-innovation-strategy-august-2024.pdf</a> (accessed 07 Jul 2025).

<sup>&</sup>lt;sup>22</sup> Department of Children, Equality, Disability, Integration and Youth, 'Autism Innovation Strategy', p. 14, <a href="https://assets.gov.ie/static/documents/autism-innovation-strategy-august-2024.pdf">https://assets.gov.ie/static/documents/autism-innovation-strategy-august-2024.pdf</a> (accessed 07 Jul 2025).

initiative will be maintained or built upon. When the current Strategy concludes in February 2026, we hope that the current Strategy will be renewed and placed on a statutory footing. In the *Programme for Government*, the Government has committed to developing a successor National Autism Strategy and to underpinning future Autism strategies by way of legislation<sup>23</sup>.

### **Suggested questions**

- Can the State provide a clear timeline and outline of the process for reviewing and updating the Equality Acts, and indicate whether it intends to include provisions addressing intersectional and multiple discrimination?
- What measures will the State take to develop a new National Autism Strategy, building on the progress of the Autism Innovation Strategy and ensuring this is underpinned by legislation?
- What measures will the State take to ensure access to fully inclusive mechanisms for challenging discrimination?

#### **Article 7: Children with Disabilities**

Irish law and policy recognises that children have the right to express their views, and that Government departments and statutory bodies must give those views due consideration when creating laws and policies that affect them. However, we find out from our community Autistic children, as with Disabled children, do not believe they have their voices heard on

<sup>&</sup>lt;sup>23</sup> Government of Ireland, 'Programme for Government 2025 Securing Ireland's Future', p. 94, <a href="https://assets.gov.ie/static/documents/programme-for-government-securing-irelands-future.pdf">https://assets.gov.ie/static/documents/programme-for-government-securing-irelands-future.pdf</a> (accessed 07 Jul 2025).

issues that affect their lives.<sup>24</sup> Laws and policies, particularly in key areas like education and health, are often created without directly engaging with Autistic children and young people, and this leads to harmful or exclusionary policies which affect their wellbeing and belonging.<sup>25</sup>

As Government departments and statutory bodies do not sufficiently seek the views of Autistic young people on key policy issues - or meaningfully reflect their experiences in policy development - Autistic children often feel that these policies are neither inclusive nor neuro-affirmative.<sup>26</sup>

The *National Framework for Children and Young People's Participation in Decision-making* recognises that all children and young people have the right to express their views. It also affirms that Autistic and Disabled children and young people have the right to access age-appropriate supports to facilitate their engagement and participation.<sup>27</sup> However, Government departments and statutory agencies do not routinely provide information in accessible formats - including Easy-to-Read materials, visual guides, or plain language documents. This indicates that accessibility is not yet embedded as a standard practice when engaging with Autistic children and young people.

This lack of consistency in good practice also extends to decision-making processes. A child's right to have their opinions and preferences considered—particularly when determining their best interests - is recognised in several areas, such as guardianship. However, there are limited opportunities to support the use of alternative forms of communication, such as

<sup>&</sup>lt;sup>24</sup> AslAm, 'Exploring the School Experiences of Autistic Children and Young People', Exploring the school experiences of Autistic children and young people. (accessed 09 Jul 2025).

<sup>&</sup>lt;sup>25</sup> AslAm, 'What We Wish You Knew - A rights-based analysis of school codes of behaviour in Ireland' p.74 67063a76a2b0a7503172f463 Code of Behaviours What We Wish You Knew Booklet digital.pdf (accessed 06 Jul 2025).

<sup>&</sup>lt;sup>26</sup> AslAm, 'What We Wish You Knew - A rights-based analysis of school codes of behaviour in Ireland' 67063a76a2b0a7503172f463 Code of Behaviours What We Wish You Knew Booklet digital.pdf (accessed 06 Jul 2025).

<sup>&</sup>lt;sup>27</sup> Department of Children, Equality, Disability, Integration and Youth, 'National Framework for Children and Young People's Participation in Decision-making' <a href="https://hubnanog.ie/participation-framework/">https://hubnanog.ie/participation-framework/</a> (accessed 07 Jul 2025).

communication devices or other preferred methods, to enable children to meaningfully participate. Furthermore, different Government departments and agencies use varying processes for providing information, which can create confusion and barriers for members of the community.

#### **Disability Services for Young People**

Ireland recognises in its laws and policies an obligation to provide disability services to Disabled and Autistic children and young people. Under the Disability Act 2005, children have a right to access an Assessment of Need, which identify whether a person has a disability. The Assessment also identifies the nature and extent of the disability, any health and education needs arising from that disability, as well as what services are required to meet those needs. The *Young Ireland Strategy*<sup>28</sup> places a focus on disability services as a key area which the Government knows that "there is a significant unmet need in disability services and therapies for children and young people"<sup>29</sup>, that "children and young people rightly expect better" and recognise "the requirement to develop high-quality services for children and young adults with disabilities that will support and empower them to live full and meaningful lives in their communities"<sup>30</sup>. However, as the Young Ireland Strategy acknowledges, children who need access to disability services, including access to assessments and therapies, face "unacceptably long" waiting times, sometimes up to 3 years or longer, to get access to the

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<sup>&</sup>lt;sup>28</sup> Department of Children, Equality, Disability, Integration and Youth, 'Young Ireland: National Policy Framework for Children and Young People 2023-2028', <a href="https://hubnanog.ie/young-ireland-national-policy-framework-for-children-and-young-people-2023-2028">https://hubnanog.ie/young-ireland-national-policy-framework-for-children-and-young-people-2023-2028</a> (accessed 07 Jul 2025).

<sup>&</sup>lt;sup>29</sup> Department of Children, Equality, Disability, Integration and Youth, 'Young Ireland: National Policy Framework for Children and Young People 2023-2028' p. 48, <a href="https://hubnanog.ie/young-ireland-national-policy-framework-for-children-and-young-people-2023-2028">https://hubnanog.ie/young-ireland-national-policy-framework-for-children-and-young-people-2023-2028</a> (accessed 07 Jul 2025).

<sup>&</sup>lt;sup>30</sup> Department of Children, Equality, Disability, Integration and Youth, 'Young Ireland: National Policy Framework for Children and Young People 2023-2028' p. 48, <a href="https://hubnanog.ie/young-ireland-national-policy-framework-for-children-and-young-people-2023-2028/">https://hubnanog.ie/young-ireland-national-policy-framework-for-children-and-young-people-2023-2028/</a> (accessed 07 Jul 2025).

supports they are deserve and are entitled to.<sup>31</sup> Reflecting this, HSE figures show that at the end of April 2025, 12,106 children were waiting for their first contact with their Children's Disability Network Team (CDNT), and of that figure, 8,298 children are waiting for more than one year for their first contact with their CDNT.<sup>32</sup>

In the *Young Ireland Strategy*, the Government identifies recruitment of health and social care professionals to staff Children's Disability Network Teams (CDNTs) as a key issue. Across Ireland, around 1 in 3 posts for CDNTs remains unfilled, in addition to recruitment and retention challenges, and this significantly impacts Autistic and Disabled children's ability to access assessments and supports at the point of need, as well as their quality-of-life. The Strategy commits to reduce waiting lists, increase capacity of CDNTs by recruiting 600 extra staff to fill multidisciplinary teams, and address waiting lists for Assessment of Need, but there is little detail on how these commitments will be achieved. <sup>33</sup> Autistic children and Disabled children are also portrayed as "service users" in the context of accessing disability services <sup>34</sup>, not as rights-holders where disability services are supports which help them meet their full range of human rights under the UNCRPD and UNCRC.

More concerningly, we see that Autistic children and young experience discrimination with accessing mental health services, and there has been an inadequate response from the State

<sup>&</sup>lt;sup>31</sup> Department of Children, Equality, Disability, Integration and Youth, 'Young Ireland: National Policy Framework for Children and Young People 2023-2028' p. 48, <a href="https://hubnanog.ie/young-ireland-national-policy-framework-for-children-and-young-people-2023-2028">https://hubnanog.ie/young-ireland-national-policy-framework-for-children-and-young-people-2023-2028</a> (accessed 07 Jul 2025).

<sup>&</sup>lt;sup>32</sup> Breakingnews.ie, 'Over 12,000 children waiting for first contact from disability teams

<sup>&#</sup>x27; https://www.breakingnews.ie/ireland/over-12000-children-waiting-for-first-contact-from-disability-teams-1770758.html (accessed 07 Jul 2025)

<sup>&</sup>lt;sup>33</sup> Department of Children, Equality, Disability, Integration and Youth, 'Young Ireland: National Policy Framework for Children and Young People 2023-2028' p. 49, <a href="https://hubnanog.ie/young-ireland-national-policy-framework-for-children-and-young-people-2023-2028/">https://hubnanog.ie/young-ireland-national-policy-framework-for-children-and-young-people-2023-2028/</a> (accessed 07 Jul 2025).

<sup>&</sup>lt;sup>34</sup> Department of Children, Equality, Disability, Integration and Youth, 'Young Ireland: National Policy Framework for Children and Young People 2023-2028' p. 48, <a href="https://hubnanog.ie/young-ireland-national-policy-framework-for-children-and-young-people-2023-2028">https://hubnanog.ie/young-ireland-national-policy-framework-for-children-and-young-people-2023-2028</a> (accessed 07 Jul 2025).

to address these issues. Autistic children are typically denied access to Child and Adolescent Mental Health Services (CAMHs) regardless of their mental health support needs based on their Autistic identity or autism diagnosis<sup>35</sup>, and often find themselves passed between services [i.e. Disability Services and Primary Care]. This is particularly concerning as research is showing that mental health difficulties is particularly common in the Autistic community -70% of Autistic children are likely to experience psychosocial disability<sup>36</sup>, and 40% of Autistic people have two or more psychosocial disabilities that affect their wellbeing<sup>37</sup>. The Department's rationale for denying access to Autistic children is due to lack of resources and where CAMHs believes that Disability Services can be better placed to deliver specific supports Autistic young people would need, and rather than allocating the additional resources to meet the needs of a cohort who are more likely to experience social exclusion, depression, anxiety, disordered eating, suicidality and cooccurring mental health conditions, who are instead refused access to mental health supports. This also conflicts with the 'no wrong door' policy for accessing mental health services highlighted in our national mental health policy, 'Sharing the Vision'. This lack of access to timely mental health services is profound - Recent reports from the HSE found that significant numbers of Autistic children and Neurodivergent children were prescribed medically unsafe doses of psychotropic medication. A recent report on CAMHs and Dual Diagnosis found that Autistic children were

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<sup>&</sup>lt;sup>35</sup> Joint Committee on Children, Equality, Disability, Integration and Youth, 'Report on CAMHS and Dual Diagnosis', May 2024.

https://data.oireachtas.ie/ie/oireachtas/committee/dail/33/joint\_committee\_on\_children\_equality\_disability\_integration\_and\_youth/reports/2024/2024-05-14\_report-on-camhs-and-dual-diagnosis\_en.pdf (accessed 07 Jul 2025)

<sup>&</sup>lt;sup>36</sup> Mosner, M., 'Rates of Co-occurring Psychiatric Disorders in Autism Spectrum Disorder using the Mini International Neuropsychiatric Interview', <a href="https://pmc.ncbi.nlm.nih.gov/articles/PMC6669096/">https://pmc.ncbi.nlm.nih.gov/articles/PMC6669096/</a> accessed 07 Jul 2025.

<sup>&</sup>lt;sup>37</sup> Rim, S.J., 'Risk of psychiatric comorbidity with autism spectrum disorder and its association with diagnosis timing using a nationally representative cohort' https://www.sciencedirect.com/science/article/abs/pii/S175094672300034X' (accessed 07 Jul 2025)

mistreated and passed between CAMHs and Disability Services, and clinical shortages has led CAMHS to prescribe children under their care with medication where therapeutic supports would have more effectively addressed their support needs. Research is also showing that Autistic people are seven times more likely to die by suicide<sup>38</sup> and six times more likely to attempt suicide.<sup>39</sup> This was also highlighted by the Joint Oireachtas Committee on Autism in its Final Report (June 2023) that they were alarmed that children have been "refused access to CAMHS services due to their autism diagnosis or their presentation of autistic traits" and in addressing the "structural discrimination" within the system also called for "a full investigation of reports from autistic people and their families that they have been refused services on the basis of an autism diagnosis or the presentation of autistic traits." 41

### **Suggested Questions**

- What measures are the State taking to address shortfalls in staffing in our Children's
   Disability Network Teams (CDNTs)?
- What is the timeline for filling in vacant posts? What are they doing to retain qualified staff?
- What is the State doing to address gaps in waiting lists and to support with meeting financial costs for families who have to seek assessments and supports via clinicians working privately?

<sup>&</sup>lt;sup>38</sup> 'Suicide and Autism - A National Crisis' <a href="https://www.ne-as.org.uk/life-saving-research-into-autism-and-suicide/">https://www.ne-as.org.uk/life-saving-research-into-autism-and-suicide/</a> (accessed 07 Jul 2025).

<sup>&</sup>lt;sup>39</sup> O'Halloran, I., 'Suicidality in autistic youth: A systematic review and meta-analysis' https://www.sciencedirect.com/science/article/pii/S0272735822000290 (accessed 07 Jul 2025)

<sup>&</sup>lt;sup>40</sup> Brennan, C., 'Camhs support withdrawn once a child's autism diagnosis is disclosed, committee told', Irish Examiner, 17 Jan 2024, <a href="https://www.irishexaminer.com/news/arid-41310982.html">https://www.irishexaminer.com/news/arid-41310982.html</a> (accessed 07 Jul 2025)

<sup>&</sup>lt;sup>41</sup> Report of the Joint Committee on Autism, Dáil Éireann debate, 07 Mar 2024 [Vol. 1051 No. 2]: <a href="https://www.oireachtas.ie/en/debates/debate/dail/2024-03-07/37/">https://www.oireachtas.ie/en/debates/debate/dail/2024-03-07/37/</a>, (accessed 07 Jul 2025).

 What measures are the HSE taking to address the issue of discrimination in accessing mental health services, such as Child and Adolescent Mental Health Services (CAMHS) on the basis of a recognised disability [i.e. an autism diagnosis]?

### **Article 8: Awareness-raising**

Despite commitments and measures undertaken by the State, stigma, prejudice and negative attitudes towards Autistic people and Disabled people continue to persist.

## **Suggested Questions:**

- How is the State addressing prejudice and negative attitudes towards Disabled people?
- How is the State ensuring awareness of the CRPD?

### **Article 9: Accessibility**

The State has "committed to ensuring that people with disabilities can access information, services and buildings and implements this commitment through anti-discrimination law, specific legislative requirements and NDIS actions."

Despite improvements in some areas, Disabled people continue to face difficulties in accessing appropriate housing, the built environment, public transport, public services and information.

<sup>&</sup>lt;sup>42</sup> Government of Ireland, 'Initial Report under the Convention on the Rights of Persons with Disabilities Ireland', <a href="https://assets.gov.ie/static/documents/draft-crpd-initial-state-report.pdf">https://assets.gov.ie/static/documents/draft-crpd-initial-state-report.pdf</a> p. 12, (accessed 07 Jul 2025)

Public transport remains inaccessible for many Disabled people, particularly those living in rural areas, due to a lack of infrastructure. Even where infrastructure exists, it is often unreliable – for example, many train and DART stations have non-functional lifts, creating serious barriers to travel<sup>43</sup>. Investment in inclusive transport is vital, but where public transport is unavailable, Disabled people need support to access their own transport or private transport. Lack of accessible transport impacts people's participation in all aspects of life.

While accessible taxis are becoming more common, major challenges remain regarding their availability, reliability, and oversight. There appears to be little systematic monitoring to assess whether the accessible taxi programme is meeting the needs of Disabled users.

### **Suggested Questions:**

- How is the accessibility of public transport infrastructure and services particularly
  in rural areas monitored and enforced, and what steps are being taken to address
  persistent issues such as non-functional lifts and long advance notice requirements?
- What mechanisms are in place to monitor and evaluate the accessibility, impact, and effectiveness of the accessible taxi programme from the perspective of Disabled users?

Article 12: Equal recognition before the law

<sup>&</sup>lt;sup>43</sup> O'Donnell, D.,, 'Protest over accessibility issues at train stations': RTÉ News, (19 Aug 2022) <a href="https://www.rte.ie/news/dublin/2022/0819/1316705-disability-protest/">https://www.rte.ie/news/dublin/2022/0819/1316705-disability-protest/</a> (accessed 07 Jul 2025)

Article 12 of the UN Convention on the Rights of Persons with Disabilities (UNCRPD) recognises that Disabled people have the same right to legal capacity as others. This means they have the right to make decisions about their own lives and to have those decisions legally recognised. The Convention also requires State Parties to provide appropriate supports to enable individuals to exercise this right, marking a fundamental shift from substituted decision-making to supported decision-making.

The commencement of the Assisted Decision-Making (Capacity) Act 2015 in April 2023 represents a significant and welcome step forward, with transformative impacts already being felt by many Autistic people in Ireland. However, there remain critical concerns that must be addressed if Ireland is to achieve full compliance with Article 12 of the UNCRPD and build on this progress.

Most notably, Ireland has entered a declaration and reservation in respect of Article 12. This reservation reflects the State's interpretation that substituted decision-making arrangements are permissible in certain circumstances, provided there are appropriate and effective safeguards. This interpretation is embedded in the 2015 Act, which—though primarily based on supported decision-making - still permits substituted decision-making in limited cases where a person is deemed to lack capacity to making decisions even with support.

In this regard, it can be argued that the 2015 Act is not fully compliant with Article 12 of the CRPD which requires replacing all forms of substituted decision-making with supported decision-making.

The right to equal recognition before the law and to participate in legal decisions about one's own life is a foundational principle of the CRPD. Therefore, we believe that Ireland's

reservation and declaration on Article 12 are contrary to the object and purpose of the Convention, and we call for their immediate withdrawal to align domestic law and policy with the full spirit and intent of the CRPD.

### **Suggested Questions:**

 What are the State's plans to withdraw the reservation and declaration on Article 12 and reform the Assisted Decision-Making (Capacity) Act to remove capacity assessments and all forms of substitute decision making?

#### **Article 13: Access to Justice**

Autistic people and Disabled people face significant barriers when accessing and engaging with the justice system in Ireland. Article 12.3 of the UN Convention on the Rights of Persons with Disabilities requires "States Parties to take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity". <sup>44</sup> This entails not only the removal of barriers to the justice system (such as physical and communication-access barriers) but also the active participation of Disabled people in court proceedings and the provision of procedural accommodations. This is essential in supporting Disabled people to successfully navigate judicial proceedings, engage with professionals and understand the processes and procedures of the justice system. Very little of the justice system in Ireland is designed in a way that is universally, or even widely, accessible; information provision, reporting mechanisms, police stations and offices, and court buildings

<sup>&</sup>lt;sup>44</sup> UN CRPD General Assembly (2007). Convention on the Rights of Persons with Disabilities, A/RES/61/106. https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-persons-disabilities.

are often not accessible to Autistic people and Disabled people.<sup>45</sup> Legal proceedings are often not conducted in a manner accessible to a diverse population.

Article 13 also requires that "those working in the field of administration of justice" receive appropriate training. 46 However, there is no compulsory training for members of the judiciary on the UNCRPD or forms of reasonable accommodation to ensure equal access to justice. We believe that the judiciary should be obligated to undertake rights-based, neuro-affirmative training on disability, the CRPD and practical skills training in communication access. 47

### **Suggested Questions**

- What plans are in place to improve the accessibility of the justice system for Autistic people and Disabled people, including physical access, communication supports, and procedural accommodations and how will this be monitored?
- Can the State outline the extent to which members of the judiciary are required to have training on the UNCRPD, and on reasonable accommodations for ensuring equal access to justice?
- What efforts has the State made to ensure courts are aware of and adhere to guidance for ensuring Disabled people and Disabled people have equal access to justice?

### Freedom from exploitation, violence and abuse – Articles 16, 6

<sup>&</sup>lt;sup>45</sup> AslAm, 'AslAm's Submission to the Joint Oireachtas Justice Committee on Courts and Courthouses', https://cdn.prod.website-files.com/6537ebf5bd64fee2cfd5af24/65e764b009c5366d62545d32 AslAm-Submission-to-the-Joint-Oireachtas-Committee-on-Courts-and-Courthouses-August-2021.pdf (accessed 07 Jul 2025)

<sup>&</sup>lt;sup>46</sup> AsIAm, 'AsIAm's Submission to the Joint Oireachtas Justice Committee on Courts and Courthouses', <a href="https://cdn.prod.website-files.com/6537ebf5bd64fee2cfd5af24/65e764b009c5366d62545d32">https://cdn.prod.website-files.com/6537ebf5bd64fee2cfd5af24/65e764b009c5366d62545d32</a> AsIAm-Submission-to-the-Joint-Oireachtas-Committee-on-Courts-and-Courthouses-August-2021.pdf (accessed 07 Jul 2025)

<sup>&</sup>lt;sup>47</sup> AslAm, 'AslAm's Submission to the Joint Oireachtas Justice Committee on Courts and Courthouses', <a href="https://cdn.prod.website-files.com/6537ebf5bd64fee2cfd5af24/65e764b009c5366d62545d32\_AslAm-Submission-to-the-Joint-Oireachtas-Committee-on-Courts-and-Courthouses-August-2021.pdf">https://cdn.prod.website-files.com/6537ebf5bd64fee2cfd5af24/65e764b009c5366d62545d32\_AslAm-Submission-to-the-Joint-Oireachtas-Committee-on-Courts-and-Courthouses-August-2021.pdf</a> (accessed 07 Jul 2025)

Further action is needed to ensure that Disabled people are free from violence and abuse.

Disability hate crime exists; however, it is underreported and misreported.

Disabled people and Autistic people who are accessing disability services and residential services remain at significant risk of abuse. In recent years, several high-profile cases have emerged, including the *Brandon Report* and the *Grace case*, exposing decades-long abuse within State-run services. Despite these deeply concerning revelations, Ireland still lacks dedicated adult safeguarding legislation, although this is being developed. During the Protection of Liberty Safeguards Consultation, we raised concerns that the Department of Health's proposals would not adequately protect the person's right to liberty or give expression to their will and preferences. AsIAm calls for Autistic people, those with lived experience, and their organisations to be central to the engagement processes. Representation should be co-produced, neuro-affirmative, and rooted in supported decision-making. Processes must ensure accessible information, value communication differences, and uphold dignity, autonomy, and rights—especially in legal contexts, where the person's will and preferences must be prioritised.

#### **Suggested Questions:**

- What measures will the State take to address under-reporting of disability-motivated hate crime?
- Can the State outline what concrete measures it will put in place to ensure that the
  development of incoming Adult Safeguarding legislation is carried out in meaningful
  consultation with Disabled people and their representative organisations, in
  accordance with Article 4.3 of the UN CRPD?

Furthermore, how will the State ensure that the legislation is fully compliant with the
principles and obligations set out under the UN CRPD, particularly with respect to
autonomy, dignity, and protection from abuse?

#### Article 19: Living independently and being included in the community

# **Enabling Independent Living**

While, as the State reports suggest, Irish disability policy places a strong emphasis on promoting independence and the inclusion of Disabled people in their communities,<sup>48</sup> AsIAm takes the view that there are significant gaps between policy and practice in this area.<sup>49</sup> In our most recent *Same Chance Report*, we found that 71% of those surveyed noted they do not believe they have access to enough supports to live independently in the community, whereas 33% of community members said their current housing situation did meet their needs.<sup>50</sup>

In 2011, the Government published its *Time to Move on from Congregated Settings* Report, however progress on this has been exceptionally slow resulting in many Disabled people continuing to live in inappropriate congregated settings. As of January 2025, there are 1,249

<sup>&</sup>lt;sup>48</sup> Department of Housing, Local Government and Heritage, 'National Housing Strategy for Disabled People 2022-2027' <a href="https://www.housingagency.ie/sites/default/files/2023-08/National-Housing-Strategy-for-Disabled-People-2022-2027.pdf">https://www.housingagency.ie/sites/default/files/2023-08/National-Housing-Strategy-for-Disabled-People-2022-2027.pdf</a> (accessed 07 Jul 2025)

<sup>&</sup>lt;sup>49</sup> AsIAm, 'AsIAm Submission to the Department of Housing and Local Government on their Statement of Strategy 2025-2028', https://cdn.prod.website-

files.com/6537ebf5bd64fee2cfd5af24/6800dbb721fab74f7c523826 AsIAm%20SubmissionStatement%20of%20Strategy%2 02025.pdf (accessed 07 Jul 2025)

<sup>&</sup>lt;sup>50</sup> AsIAm, 'Same Chance Report 2025' https://cdn.prod.website-

files.com/6537ebfefba7b3c24a18e646/67e572276f39ff1d6d830135 Version%203%20Digital%20Full%20AslAm%20Same% 20Chance%20Report.pdf (accessed 07 Jul 2025).

Disabled people under the age of 65 living in nursing homes due to a lack of in-community supports<sup>51</sup>.

Our engagement with Autistic people has highlighted the significant barriers our community faces in accessing supports, securing appropriate housing, and feeling safe and protected within their communities. We are particularly concerned about the high levels of social exclusion experienced by Autistic people across Irish society, which was consistently identified as a major barrier to community participation.

Many Autistic people told us they feel that being Autistic itself is a barrier to engaging with their communities, services, supports, and public environments and services. This exclusion has a direct and harmful impact on their wellbeing. Community experiences reflect that Autistic people often feel isolated and excluded due to a lack of access to essential services and supports - including accessible housing, public transport, inclusive public environments and services, and independent living supports such as personalised budgets and Personal Assistance Services.

## **Personal Assistance Services**

Personal Assistance Services (PAS) are central to facilitating independent living for Disabled people, as recognised under Article 19 of the UNCRPD. However, in Ireland, Disabled people do not have a right to access Personal Assistance, even when these services are essential to

<sup>&</sup>lt;sup>51</sup> The Journal, 'I don't want to be here forever': The hidden struggle of middle-aged adults living in nursing homes' <a href="https://www.thejournal.ie/middle-aged-adults-living-in-nursing-homes-lack-of-disability-care-supports-6679801-Apr2025/">https://www.thejournal.ie/middle-aged-adults-living-in-nursing-homes-lack-of-disability-care-supports-6679801-Apr2025/</a>
O1 Apr 2025, (accessed 07 Jul 2025)

their autonomy and participation in community life. There is also no standardised approach to assessing the need for PAS, resulting in inequitable and inconsistent access to Personal Assistance across Ireland.

Resourcing alone is not the issue. Among those who do receive PAS, the average allocation is just 42 minutes per day<sup>52</sup> - which is clearly inadequate to support meaningful independence, personal choice, or dignity in everyday life. In the absence of a legal entitlement to personal assistance, Disabled people are left reliant on discretionary systems that often fail to uphold their rights under the UNCRPD.

### Supporting community living

To live and to fully participate in their local community, Autistic people and Disabled people need timely access to supports to help to participate in the community. However, in Ireland, significant barriers persist. Many services are still provided by voluntary or charitable organisations and are often dependent on a formal diagnosis rather than actual need, which is inconsistent with a human rights-based model of disability.

Across multiple sectors, people with disabilities face lengthy waiting lists and delays in accessing essential supports. For children, delayed access to early intervention services further undermines their rights under Article 19 of the UN CRPD, which guarantees the right to live independently and be included in the community.

<sup>&</sup>lt;sup>52</sup> Disability Federation of Ireland,' Personal Assistance Services Position Paper' <a href="https://www.disability-federation.ie/assets/files/pdf/dfi">https://www.disability-federation.ie/assets/files/pdf/dfi</a> personal assistance services position paper final 14102024.pdf (07 Jul 2025)

Currently over 4,200 children are on waiting lists for Children and Adolescent Mental Health Services (CAMHS) and 640 of those were waiting over 12 months.<sup>53</sup> Some services, and parts of the country, experience more extensive delays than others with many describing access to essential health services and assistive technology as a 'postcode lottery'. For example, waiting lists for speech and language therapy were among the longest with 18,934 children on the waiting list for initial assessment<sup>54</sup>, 5,154 of these children are waiting more than one year, and 539 are waiting more than two years. 8,829 children are on a waiting list for psychology services, with one child waiting over 13.5 years to see a psychologist.<sup>55</sup>

When children do access supports, there is often a lack of coordination across services and sectors, including service providers. Disability services, mental health services, and primary care, whilst funded by the Health Service Executive, may be provided by a mix of disability service providers and State services. There is no structured transition process from child to adult services in the health sector or clear linked pathways between services. Progressing Disability Services for Children and Young People aims to address many of these issues with consistency and access. However, there are significant issues with its implementation, recruitment of staff and engagement with children and families. <sup>56</sup> 12,106 children were waiting for initial contact from a specialised Child Disability Network Team (CDNT). <sup>57</sup>

<sup>&</sup>lt;sup>53</sup> Bray, J., 'Hundreds of children waiting more than a year to access mental health services', <a href="https://www.irishtimes.com/health/2025/02/18/hundreds-of-children-waiting-more-than-a-year-to-access-mental-health-services/">https://www.irishtimes.com/health/2025/02/18/hundreds-of-children-waiting-more-than-a-year-to-access-mental-health-services/</a> The Irish Times, 18 Feb 2025, (accessed 07 Jul 2025)

<sup>&</sup>lt;sup>54</sup> O'Regan, E., 'Almost 13,000 children waiting to be seen by HSE disability teams in hopes of securing specialist support' <a href="https://www.independent.ie/irish-news/almost-13000-children-waiting-to-be-seen-by-hse-disability-teams-in-hopes-of-securing-specialist-support/a672306720.html">https://www.independent.ie/irish-news/almost-13000-children-waiting-to-be-seen-by-hse-disability-teams-in-hopes-of-securing-specialist-support/a672306720.html</a> Irish Independent, 30 Apr 2025, (accessed 07 Jul 2025)

<sup>55 &#</sup>x27;Child waiting 13 years for psychological service, figures show. Breakingnews.ie,

https://www.breakingnews.ie/ireland/child-waiting-13-years-for-psychological-service-figures-show-1781371.html (accessed 08 Jul 2025).

<sup>&</sup>lt;sup>56</sup> Inclusion Ireland (2022), 'Progressing Disability Services for Children and Young People: Patient Experience Survey
Report': <a href="https://inclusionireland.ie/wp-content/uploads/2022/03/Inclusion-Ireland-Progressing-Disability-Services-Report-March-2022.pdf">https://inclusionireland.ie/wp-content/uploads/2022/03/Inclusion-Ireland-Progressing-Disability-Services-Report-March-2022.pdf</a>

<sup>&</sup>lt;sup>57</sup> BreakingNews.ie, 'Over 12,000 children waiting for first contact from disability teams

Under the Disability Act 2005, children are entitled to have their need for services and supports assessed. The Assessment of Need (AON) process is subject to clear guidance on when the review will take place, how these reviews will be conducted and the child's identified support needs. However, the AON process does not provide an entitlement to access services but outlines how a child's support needs would be addressed using a Service Statement. This process has been met with significant criticism due to families facing significant delays for assessments, and long waiting lists to accessing supports. The AON does not take a holistic, rights-based approach to considering the child's support needs and reflects a medical model approach where support needs are determined by a child's functional capacity. In general, the 2005 Act needs to be reviewed, and many provisions contained within it are outdated; it does not conform with the human rights model of disability in its definition or provisions and is therefore in need of review.

### **Suggested Questions**

- What concrete steps is the State taking to accelerate the closure of congregated settings and reduce the number of Disabled people under 65 living in nursing homes and other institutional settings, in line with the commitments made in the "Time to Move on from Congregated Settings" policy?
- How is the State addressing the extensive waiting lists and delays for essential community-based supports and early intervention services for Disabled children,

<sup>&#</sup>x27;https://www.breakingnews.ie/ireland/over-12000-children-waiting-for-first-contact-from-disability-teams-1770758.html 08 Jun 2025 (accessed 07 Jul 2025).

<sup>&</sup>lt;sup>58</sup> Section 7, Disability Act 2005, <a href="https://www.irishstatutebook.ie/eli/2005/act/14/enacted/en/print.html">https://www.irishstatutebook.ie/eli/2005/act/14/enacted/en/print.html</a> (accessed 07 Julm 2025)

including therapies and mental health services, to comply with its obligations under Article 19 of the UN CRPD?

 What measures are being taken to improve the coordination and integration of services across disability, mental health, primary care, and acute care sectors, particularly to support smoother transitions from child to adult services?

### **Article 24: Education**

In Ireland, children are entitled to additional support to access an "appropriate education" under the Education of Persons with Special Needs (EPSEN) Act 2004. <sup>59</sup> However, sections of the EPSEN Act have not been fully commenced. This has meant significant numbers of Autistic and Disabled children continue to experience segregation and exclusion within the education system. This has left many families in our community struggling to secure school places, facing lengthy waiting lists for essential supports, or having to engage in advocacy or legal action to uphold their child's right to education.

The Department of Education recently <u>published a review into the EPSEN Act</u> and among the 51 recommendations is to develop a pathway for rolling out an education system which is consistent with Article 24 and General Comment 4 of the UNCRPD.<sup>60</sup> The Review recommended that the Department take a "twin-track" approach to transitioning towards a

<sup>&</sup>lt;sup>59</sup> Section 2, Education of Persons with Special Needs Act 2004. https://www.irishstatutebook.ie/eli/2004/act/30/enacted/en/html (accessed 07 Jul 2025)

<sup>&</sup>lt;sup>60</sup> Department of Education, 'Review of The Education for Persons with Special Educational Needs (EPSEN) Act 2004', <a href="https://assets.gov.ie/static/documents/Report on the Review of The Education for Persons with Special Educational Needs.pdf">https://assets.gov.ie/static/documents/Report on the Review of The Education for Persons with Special Educational Needs.pdf</a> (accessed 07 Jul 2025).

more inclusive education system.<sup>61</sup> A more inclusive education system means that the Department must ensure that every Autistic child has a school place with supports which meet their needs presently, whilst also building towards longer-term reforms which support all students, regardless of support needs, to go to their local school with their peers.<sup>62</sup> We recently sent a submission to the Irish National Council for Curriculum and Assessment, where we highlighted the necessary changes to School Curriculum to support these objectives and make subjects, environments and class materials more accessible and intuitive to Autistic Students in accordance with Universal Design for Learning.<sup>63</sup>

However, we see a range of issues which have a disproportionate impact on Autistic people's experiences at school. Many children are on waiting lists for places in special schools and autism classes, where they may have to travel long distances, far away from their community, to access a suitable school place as their support needs could not be met in their local school. When Disabled people access mainstream education, there is a lack of support available to facilitate their full participation at school, or full access to the curriculum. We find that this lack of full access to school curriculums also extends to children in autism classes and special schools. Autistic children and Neurodivergent children are among the cohorts of

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<sup>&</sup>lt;sup>61</sup> Department of Education, 'Review of The Education for Persons with Special Educational Needs (EPSEN) Act 2004',p. 92, <a href="https://assets.gov.ie/static/documents/Report on the Review of The Education for Persons with Special Educational Needs.pdf">https://assets.gov.ie/static/documents/Report on the Review of The Education for Persons with Special Educational Needs.pdf</a> (accessed 07 Jul 2025).

<sup>&</sup>lt;sup>62</sup> AsIAm, 'AsIAm Submission to the Department of Education on Proposed Reforms on the Education of Persons with Special Education Needs (EPSEN) Act 2004', <a href="https://cdn.prod.website-files.com/6537ebf5bd64fee2cfd5af24/65e7332acda93bda76f23607\_AsIAm-submission-on-the-EPSEN-Act-Reforms.pdf">https://cdn.prod.website-files.com/6537ebf5bd64fee2cfd5af24/65e7332acda93bda76f23607\_AsIAm-submission-on-the-EPSEN-Act-Reforms.pdf</a> (accessed 07 Jul 2025)

<sup>&</sup>lt;sup>63</sup> AslAm, 'AslAm Submission to the National Council for Curriculum and Assessment on their Public Consultations on the Draft Primary Curriculum Specifications in Arts Education; Modern Foreign Languages (MFL) in the Primary Language Curriculum; Social and Environmental Education (SEE); Science, Technology and Engineering Education (STE); and Wellbeing' https://cdn.prod.website-

files.com/6537ebfefba7b3c24a18e646/667d77c622cf29a83b4f531d\_AsIAm%20Submission%20to%20the%20NCCA%20on %20the%20Primary%20Curriculum%20Framework.pdf (accessed 07 Jul 2025)

<sup>&</sup>lt;sup>64</sup> AslAm, 'AslAm Submission to the Department of Education on Proposed Reforms on the Education of Persons with Special Education Needs (EPSEN) Act 2004', <a href="https://cdn.prod.website-">https://cdn.prod.website-</a>

files.com/6537ebf5bd64fee2cfd5af24/65e7332acda93bda76f23607\_AsIAm-submission-on-the-EPSEN-Act-Reforms.pdf (accessed 07 Jul 2025)

Disabled people particularly affected by a lack of support and lack of understanding on both how they can feel safe and supported at school and how they can be included in the classroom. Autistic children tell us that schools' lack of understanding, training and resources for staff to support them at school and feel that school policies can typically penalise Autistic students for presenting Autistic traits.<sup>65</sup>

#### **Codes of Behaviour**

Autistic children are disproportionately affected by policies and frameworks such as Codes of Behaviour, which we highlighted in a recently published independent report on the use and practice of Codes of Behaviour in Irish Schools, "What We Wish You knew: A rights-based analysis of school codes of behaviour". In this Report, we carried out a critical analysis of 40 randomly selected School Codes of Behaviour, and we found that none of the School Codes analysed were fully rights compliant, and that school policies perpetuated an ableist attitude towards autism, and to educating Autistic people. <sup>66</sup>The report also highlighted that Autistic students' perspectives were often excluded from designing, consulting or reviewing of these policies. The Report makes several recommendations which include students co-producing a rights-compliant Code of Behaviour, together with capacity building and guidance for both students and adult professionals, replacing rewards and sanctions, including provision of

<sup>&</sup>lt;sup>65</sup> AsIAm,'What We Wish You Knew A rights-based analysis of school codes of behaviour in Ireland' https://cdn.prod.website-

<sup>&</sup>lt;sup>66</sup> AsIAm,'What We Wish You Knew A rights-based analysis of school codes of behaviour in Ireland' https://cdn.prod.website-

files.com/6537ebf5bd64fee2cfd5af24/67063a76a2b0a7503172f463 Code%20of%20Behaviours%20What%20We%20Wish %20You%20Knew%20Booklet%20digital.pdf (accessed 07 Jul 2025)

reasonable accommodations in all classrooms, and removing ableist or behaviourist language and provisions from school Codes.<sup>67</sup>

#### **Reduced Timetables**

Placing Autistic children and Disabled children on reduced timetables happens frequently in Irish schools. A report by Inclusion Ireland found that approximately one in four children with an intellectual or developmental disability had been placed on reduced timetables and this lasted for more than 20 days for half of these children<sup>68</sup>. This is despite guidelines from the Department of Education specifying that it should only occur in circumstances where it may be "part of a transition or reintegration intervention, based on the needs of the individual students<sup>169</sup> and should not be used as a sanction. A key reason schools may place Autistic children on a reduced timetable is that as a consequence or feeling upset, distressed or dysregulated by their needs not being met, the child may display 'challenging behaviour' or may be seen as being too 'bold' or 'disruptive' – a stigmatising label for many Autistic and Disabled children with disabilities which has a wider negative impact on their school experiences. It does not recognise that what is often deemed 'challenging behaviour' is as a response to environmental factors, lack of accessibility and lack of support.

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<sup>&</sup>lt;sup>67</sup> AsIAm,'What We Wish You Knew A rights-based analysis of school codes of behaviour in Ireland' https://cdn.prod.website-

files.com/6537ebf5bd64fee2cfd5af24/67063a76a2b0a7503172f463 Code%20of%20Behaviours%20What%20We%20Wish %20You%20Knew%20Booklet%20digital.pdf (accessed 07 Jul 2025)

<sup>&</sup>lt;sup>68</sup> Inclusion Ireland (2019), Education, Behaviour and Exclusion The experience and impact of short school days on children with disabilities and their families in the Republic of Ireland.

<sup>&</sup>lt;sup>69</sup> Department, of Education, 'The Use of Reduced School days Guidelines for schools on recording and notification of the use of Reduced School days', <a href="https://childrensrights.ie/wp-content/uploads/2023/02/The-Use-of-Reduced-School-days.pdf">https://childrensrights.ie/wp-content/uploads/2023/02/The-Use-of-Reduced-School-days.pdf</a> (accessed 07 Jul 2025)

#### **Seclusion and restraint**

Seclusion and restraint also continue to be used as a response to 'challenging behaviour' or as a disciplinary measure in some Irish schools. Examples include children with disabilities being locked in a room, forcibly removed from spaces or held down. Such practices directly violate Disabled children's right to education, bodily integrity, liberty and security and non-discrimination.

In 2024, the Department of Education recently published Guidelines on the use of restraint and seclusion in Irish schools, titled 'Understanding Behaviours of Concern and Responding to Crisis Situations Guidelines for Schools in Supporting Students'. The Guidelines cover how practices like seclusion and restraint are used in schools and will come into force in September 2025. The Guidelines state that schools should focus on de-escalation and prevention and prohibits schools from using seclusion. Schools will now have to report incidents where physical restraint is used on students to the NCSE (National Council for Special Education). However, AsIAm and other organisations highlight significant concerns regarding this. The current reporting mechanism for restraint in schools does not comply with the Children First Act. While schools must report incidents to the NCSE, this body cannot investigate, and there is no clear referral pathway to Tusla. The Department claims the Children First guidelines apply but fails to clarify how. Key safeguarding concerns raised by organisations were not addressed. The system allows schools to self-report without independent oversight, lacks mandatory training, parental consent, or inspection requirements, and falls short of safeguarding standards used in other settings like prison and social care. 70 The Department

<sup>70</sup> https://asiam.ie/what-we-do/policy

of Education should strengthen the Guidelines on seclusion and restraint to meet child protection and human rights standards. These measures include an independent review centred on child safeguarding; mandatory, rights-based training for school staff; a formal referral pathway to Tusla with oversight powers; and a requirement for schools to have rights-based policies and undergo regular inspections.

#### **Individualised support**

Many Autistic students who attend mainstream school do so with support from a Special Needs Assistant (SNA) or get support from a Special Education Teacher (SET). Although the number of SNAs and SETs have increased in recent years, these are insufficient to fully meet the demand for supports from communities who need them to fully engage and participate at school.<sup>71</sup>

Recently the <u>Access and Inclusion Model (AIM)</u> was introduced to provide access to the Early Childhood Care and Education (ECCE) scheme to children with disabilities in 2016. While many of the provisions under AIM welcomed in theory, our members have highlighted issues with its operation in practice. Under AIM guidelines funding can be provided to enable an Early Learning Centre to provide additional assistance in the preschool class. However, such assistance only decreases the child-to-adult ratio and does not ensure that a Disabled child will receive the individualised support they may require. Additionally, individuals hired under

<sup>71</sup> Special Educational Needs, Dáil Éireann Debate, Question 267- 27 March 2025 https://www.oireachtas.ie/en/debates/question/2025-03-27/267/ (accessed 07 Jul 2025).

this scheme can only provide support for 3 hours a day and there is no obligation for individuals to have any training in relation to disability, accessibility or equality. Therefore, while the scheme provides some support in pre-school it does not ensure that children with disabilities will have access to the individualised support they require in line with a human rights model.

### **Suggested Questions**

- What concrete steps is the State taking to fully commence and implement the EPSEN
   Act 2004, ensuring that it aligns with the UNCRPD's mandate for inclusive education?
- How does the State plan to address the increasing reliance on segregated special classrooms and special schools, and what measures will be put in place to promote and expand inclusive education in mainstream schools?
- What policies or actions are being taken to reduce and ultimately eliminate the
  practice of placing Disabled children on reduced timetables, especially when this
  practice disproportionately affects children with intellectual or developmental
  disabilities?
- How is the State working to abolish the use of seclusion and restraint in schools and to replace these with human rights-based approaches that support Disabled children appropriately?
- Given the ongoing shortages of Special Needs Assistants (SNAs) and the reassignment of SNAs to teaching roles, what plans does the State have to ensure sufficient and properly trained staff are available to support Disabled children in education?

- How will the State improve the Access and Inclusion Model (AIM) to guarantee individualised, adequately trained support for Disabled children in early childhood education settings, consistent with a human rights approach?
- What data is collected and reviewed by the State to monitor the effectiveness of inclusive education policies, and how is this data used to inform improvements in access and support for Disabled children?

#### Article 25: Health

Autistic and Disabled people's lives are particularly impacted by barriers to accessing healthcare services, which has a significant impact on Autistic and Disabled people being able to exercise their rights.

In our advocacy work, we often highlight that many Autistic people and their families face significant barriers in accessing essential services and supports. Our community frequently experiences distress, anxiety, and humiliation when required to navigate processes that demand the disclosure of sensitive or personal information—often without clarity about how this information will be used. They may also be compelled to repeatedly prove the disabling aspects of being Autistic, or demonstrate the emotional toll on families, in order to receive the support, they need.

Understaffed clinical teams, including Children's Disability Network Teams (CDNTs), is affecting timely access to essential supports and services, and this was a key issue that we highlighted in a submission we made to CORU, the Irish regulatory body responsible for overseeing many clinical and social care professions. We highlighted the impact of families having to navigate extensive waiting lists to get access to diagnostic assessments and supports like therapies. We also highlight that training, and professional standards should promote a positive Autistic identity and recognise, support and learn from Autistic peoples lived experiences. <sup>72</sup>

From a national perspective, we observe that not all clinical professionals are held to clear, robust standards for professional development and training. Furthermore, the qualifications required to provide supports or interventions are often opaque. We frequently encounter cases where clinical professionals are not required to hold specific qualifications or specialisms in relevant disciplines to conduct autism assessments.

AsIAm is deeply concerned that no system of statutory regulation and registration for psychology where 'psychologist' is a protected title, is in operation.<sup>73</sup> We have seen that the absence of a regulatory framework provides opportunities for 'fake psychologists' to diagnose people with no evidence of clinical training, qualifications or expertise, or formal system of oversight or accountability. This absence has significantly harmed Autistic people and families across Ireland, given the need for psychologists to deliver autism assessments and post-

07 Jul 2025).

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<sup>&</sup>lt;sup>72</sup> AslAm, 'AslAm Submission to CORU on their Public Consultations on Draft Framework PreRegistration Education and Training Requirements and Standards of Proficiency', <a href="https://cdn.prod.website-files.com/6537ebfefba7b3c24a18e646/664f5af212c7ce3655da0ac7">https://cdn.prod.website-files.com/6537ebfefba7b3c24a18e646/664f5af212c7ce3655da0ac7</a> AslAm%20Submission%20to%20CORU.pdf (accessed

<sup>&</sup>lt;sup>73</sup> AslAm, 'AslAm Submission to CORU on their Public Consultations on Draft Framework PreRegistration Education and Training Requirements and Standards of Proficiency', <a href="https://cdn.prod.website-files.com/6537ebfefba7b3c24a18e646/664f5af212c7ce3655da0ac7\_AslAm%20Submission%20to%20CORU.pdf">https://cdn.prod.website-files.com/6537ebfefba7b3c24a18e646/664f5af212c7ce3655da0ac7\_AslAm%20Submission%20to%20CORU.pdf</a> (accessed 07 Jul 2025).

diagnosis supports. Autistic people and families share stories of receiving assessment reports from people claiming to be Psychologists but with no recognised qualifications to support their work. We also hear of similar stories of people using this lack of regulation to promote medically unsafe, non-evidence-based 'interventions' which claim to 'treat' or 'cure' an Autistic person. This causes a great deal of distress and harm to members of our community who are desperately seeking support, often at great personal and financial cost.

This lack of standardisation also creates uncertainty for the vast majority of psychologists who do work ethically and with professional integrity. Their clinical judgement or expertise may be questioned in critical situations where a person's need for support is being assessed. <sup>74</sup> This stands in stark contrast to other regulated clinical professions – such as Speech and Language Therapy, Occupational Therapy, and Social Work - which are legally protected and governed by rigorous regulatory standards that uphold the quality and safety of their vital work.

#### **Access to Mental Health**

Research suggests that Autistic people and Disabled people are significantly more likely to experience co-occurring mental health conditions. Autistic people face significant structural barriers to accessing mental health supports. Autistic people still experience discrimination in mental health services, meaning that they don't get access to the support when they need it. An Autistic person's diagnosis is often used to justify moving them to different services, such

<sup>&</sup>lt;sup>74</sup> AslAm, 'AslAm Submission to CORU on their Public Consultations on Draft Framework PreRegistration Education and Training Requirements and Standards of Proficiency', <a href="https://cdn.prod.website-files.com/6537ebfefba7b3c24a18e646/664f5af212c7ce3655da0ac7\_AslAm%20Submission%20to%20CORU.pdf">https://cdn.prod.website-files.com/6537ebfefba7b3c24a18e646/664f5af212c7ce3655da0ac7\_AslAm%20Submission%20to%20CORU.pdf</a> (accessed)

<sup>07</sup> Jul 2025).

as Primary Care and Adult Mental Health Services (AMHS).<sup>75</sup> This has a significant impact on their wellbeing and the types of support they receive. As many community members require support from both mental health and disability services, we need to see a "no wrong door" policy delivered in practice, in line with our national mental health policy <u>Sharing the Vision</u>.

### **Suggested Questions**

- How are the State addressing health inequalities, including inequality in life expectancy and end-of-life care, for Disabled people, particularly women, people with intellectual disabilities and mental health conditions?
- How is the State ensuring sufficiently funded and appropriate mental health services
   that enable people to reach the highest attainable standard of mental health?
- What steps are the State taking to ensure that healthcare services, including mental health services for the Autistic people are fully accessible, and rights-based?
- What steps are the State taking to ensure that healthcare services for people with communication support needs are fully accessible?

# **Article 27: Work and Employment**

<sup>&</sup>lt;sup>75</sup> AslAm, 'AslAm Submission to CORU on their Public Consultations on Draft Framework PreRegistration Education and Training Requirements and Standards of Proficiency', <a href="https://cdn.prod.website-files.com/6537ebfefba7b3c24a18e646/664f5af212c7ce3655da0ac7\_AslAm%20Submission%20to%20CORU.pdf">https://cdn.prod.website-files.com/6537ebfefba7b3c24a18e646/664f5af212c7ce3655da0ac7\_AslAm%20Submission%20to%20CORU.pdf</a> (accessed 07 Jul 2025).

Ireland has the lowest employment rate for Disabled people in the EU, at 38.2% and has the largest employment gap between Disabled people and non-Disabled people.<sup>76</sup> From our own community's perspective, we found that Autistic people faced specific barriers to accessing employment. Autism Europe suggests that the employment rate of Autistic people may be as low as 5-15%<sup>77</sup>

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 from not having the same chance to be accepted and included in Irish society, from inaccessible or exclusionary workplaces or working practices."<sup>78</sup>

Autistic peoples' experiences within the workplace also deeply affects their wellbeing, identity and sense of belonging. When in the right job with the right supports, many Autistic people hold positive attitudes towards employment, noting having work provides 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

<sup>&</sup>lt;sup>76</sup> European Commission, 2025 Country Report – Ireland, p. 90, <u>7ec5fe18-b881-4140-b86a-7b22cb7a8580\_en</u> (accessed 20 Jun 2025).

<sup>&</sup>lt;sup>77</sup> Autism Europe, 'Bridging the Autism Employment Gap in Europe: A Compendium of Current Practices and Initiatives', p. 3, <a href="https://www.autismeurope.org/wp-content/uploads/2023/10/ENG\_INFUSE-Compendium-of-best-practices.pdf">https://www.autismeurope.org/wp-content/uploads/2023/10/ENG\_INFUSE-Compendium-of-best-practices.pdf</a> (accessed 26 Jun 2025)

<sup>&</sup>lt;sup>78</sup> AsIAm, 'AsIAm Submission to the Department of Social Protection on Disability Income Supports Reform', p.49, https://cdn.prod.website-

files.com/6537ebf5bd64fee2cfd5af24/6632576c36769aa351eb2f9e\_AsIAm%20Green%20Paper%20Submission.pdf (accessed 27 Jun 2025)

adapt their ways of being or processing the world to meet their employer's expectations. 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 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.

Through our engagement with our community, in a report called *Autism in the Workplace*, 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. <sup>79</sup> 58% of Autistic people believed that requesting Reasonable Accommodation would hinder their prospects of securing their preferred role. <sup>80</sup> 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.

#### The Comprehensive Employment Strategy for People with Disabilities (2014–2024)

To improve access to employment for Disabled people, the State introduced the *Comprehensive Employment Strategy for People with Disabilities (2014–2024)*<sup>81</sup>. However, this Strategy did not include any specific metrics or targets relating to tackling gender inequality in employment for Disabled women. A National Disability Authority (NDA) review of the Strategy found that, overall, the Strategy did not result in meaningful improvements in employment outcomes for Disabled people<sup>82</sup>.

Over its lifetime, there has been no substantial reduction in the employment gap, in fact the number of Disabled individuals relying on social welfare increased during this period.<sup>83</sup> The NDA's review identified the absence of meaningful outcome indicators as a significant

<sup>&</sup>lt;sup>79</sup> AsIAm, 'Autism in the Workplace', <a href="https://cdn.prod.website-">https://cdn.prod.website-</a>

files.com/6537ebfefba7b3c24a18e646/65f201020206226bbd209458\_Autism-in-the-Workplace-Report-New-Logo.pdf (accessed 26 Jun 2025)

<sup>&</sup>lt;sup>80</sup> AsIAm, 'Autism in the Workplace', <a href="https://cdn.prod.website-">https://cdn.prod.website-</a>

files.com/6537ebfefba7b3c24a18e646/65f201020206226bbd209458 Autism-in-the-Workplace-Report-New-Logo.pdf (accessed 26 Jun 2025).

 $<sup>^{81}</sup>$  Government of Ireland, 'The Comprehensive Employment Strategy for People with Disabilities (2014–

<sup>2024)&#</sup>x27; Comprehensive Employment Strategy for People with Disabilities 2015–2024 (accessed 07 Jul 2025).

<sup>&</sup>lt;sup>82</sup> National Disability Authority, <u>Final Review of Progress under the Comprehensive Employment Strategy for People with</u> <u>Disabilities</u> (2015–2024) (February 2025)

<sup>&</sup>lt;sup>83</sup> National Disability Authority, <u>Final Review of Progress under the Comprehensive Employment Strategy for People with Disabilities</u> (2015–2024) (February 2025) (accessed 07 Jul 2025)

limitation of the Strategy. Apart from setting an overall employment rate target for Disabled people, the Strategy lacked specific, measurable goals to track progress in key areas.

## Public sector recruitment targets for Disabled people

In the public sector, there is a stated target for 6% of employees to be Disabled people. <sup>84</sup> This figure is disproportionately low, particularly when compared to the fact that approximately 22% of the population in Ireland identifies as Disabled. <sup>85</sup> Furthermore, this target is applied across the public sector, rather than disaggregated by grade or level. As a result, there is no obligation to ensure that Disabled employees are equitably represented across senior positions or are progressing in their careers.

A significant gap in data collection further compounds this issue. There is a lack of comprehensive reporting on the number of Disabled employees at different grades, and no tracking of career advancement. This absence of detailed, disaggregated data makes it difficult to identify and address the systemic barriers Disabled workers face within the public sector.

Despite policy commitments to increase Disabled people's employment in the public sector, significant barriers remain - particularly in the areas of recruitment and career progression.

Recruitment processes, including open competitions and assessment procedures, have

<sup>84</sup> National Disability Authority, Employment of Persons with Disabilities in the Public Sector 'https://nda.ie/monitoring/monitoring/employment-of-persons-with-disabilities-in-the-public-sector' (accessed 07 Jul 2025)

<sup>85</sup> Central Statistics Office, Census 2022 Profile 4 - Disability, Health and Carers, <a href="https://www.cso.ie/en/releasesandpublications/ep/p-cpp4/census2022profile4-disabilityhealthandcarers/">https://www.cso.ie/en/releasesandpublications/ep/p-cpp4/census2022profile4-disabilityhealthandcarers/</a> (accessed 07 Jul 2025).

become increasingly inaccessible. Public appointment procedures that were once accessible

have now been outsourced to online platforms that fail to meet accessibility standards. These

inaccessible digital assessments effectively prevent many Disabled candidates from

successfully entering civil service roles.

In addition, disparities exist in the implementation of flexible working arrangements, which

disproportionately affects Disabled employees. While flexi-time policies are available, they

are often limited to time spent physically in the office. Remote and hybrid workers - many of

whom are Disabled and rely on remote work as a necessary accessibility measure - are

frequently excluded from these arrangements.

**Suggested Questions** 

How will the State ensure that future employment strategies include clear,

measurable targets specifically aimed at increasing employment rates for Disabled

people? What evaluation mechanisms are planned for this strategy to monitor

progress on employment outcomes for Disabled people?

What concrete measures will the State implement to ensure that recruitment,

assessment, and career progression processes within its own employment structures

are fully accessible to Autistic people and Disabled people, including those requiring

reasonable accommodations when changing roles or working remotely?

Article 28: Adequate standard of living and social protection

47

Poverty is a significant and persistent issue facing Disabled people and Autistic people in Ireland. National poverty statistics show that consistent poverty rate for Disabled people in Ireland is 19% - four times higher than the national average. 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. National statistics also found that Disabled people unable to work were at higher risk of poverty, 32.5%, compared to 5.4% who were employed.

The European Commission has highlighted in recent Semester Reports that the Government needs to urgently address disability poverty, citing that whilst some measures gave relief, the current social protection system was not adequately compensating for the additional costs of disability. Reflecting this, 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. Ireland also ranks 17th out of 27 EU countries for addressing at risk of poverty and severe material deprivation for Disabled people.

Several factors contribute to the persistently high levels of poverty and deprivation experienced by Autistic and Disabled people. These include disproportionately high rates of unemployment and underemployment, social protection payments that fail to cover

<sup>&</sup>lt;sup>86</sup> 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).

<sup>&</sup>lt;sup>87</sup> 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)

<sup>88</sup> 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).

<sup>&</sup>lt;sup>89</sup> European Commission, 2025 Country Report – Ireland, p. 96, <u>7ec5fe18-b881-4140-b86a-7b22cb7a8580</u> en (accessed 20 Jun 2025).

<sup>&</sup>lt;sup>90</sup> European Commission, 2025 Country Report – Ireland, p. 96, <u>7ec5fe18-b881-4140-b86a-7b22cb7a8580</u> en (accessed 20 Jun 2025).

<sup>91</sup> EUROSTAT, https://ec.europa.eu/eurostat/databrowser/view/hlth\_dpe010/default/bar?lang=en\_accessed 26 Jun 2025

additional disability-related costs, and restrictive means testing that limits access to financial supports. AsIAm's *Same Chance Report* for 2025 found that 79% of community members have additional costs because they or their family member is Autistic. 92 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;
- Purchasing sensory items;
- Adapting the home to make it more accessible;
- Loss of income due to caregiving responsibilities;

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. <sup>93</sup> 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. <sup>94</sup>

<sup>92</sup> AsIAm, 'Same Chance Report', https://cdn.prod.website-

files.com/6537ebfefba7b3c24a18e646/67e572276f39ff1d6d830135 Version%203%20Digital%20Full%20AsIAm%20Same% 20Chance%20Report.pdf (accessed 26 Jun 2025)

<sup>93</sup> AsIAm, 'Same Chance Report', https://cdn.prod.website-

files.com/6537ebfefba7b3c24a18e646/67e572276f39ff1d6d830135\_Version%203%20Digital%20Full%20AsIAm%20Same% 20Chance%20Report.pdf (accessed 26 Jun 2025)

<sup>&</sup>lt;sup>94</sup> 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)

The Indecon *Cost of Disability Report*, commissioned by the Department of Social Protection, provided comprehensive analysis on the impact that disability-related costs experienced by Disabled people had on their living standards. The report concluded that "there are significant additional costs faced by individuals with a disability which are currently not met by existing programmes or by social welfare payments". 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. 95The 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. 96 To illustrate this, a recent Economic and Social Research Institute Report asserts that having a Disabled household member is a contributing factor to a family experiencing poverty, and regardless of their income, are much more likely to experience material deprivation. 97

A more recent report from the Economic and Social Research Institute, commissioned by the Irish Human Rights and Equality Commission, published more up-to-date statistics on the cost of disability in Ireland. The Report found that households with a Disabled member "face significant financial burdens related to disability and have very high at risk of poverty (AROP) rates."98 The Report found that:

• Households are more likely to be at risk of poverty and have a lower standard of living;

<sup>&</sup>lt;sup>95</sup> Indecon, 'Cost of Disability Report', p.14, <a href="https://assets.gov.ie/static/documents/the-cost-of-disability-in-ireland-research-report.pdf">https://assets.gov.ie/static/documents/the-cost-of-disability-in-ireland-research-report.pdf</a> (accessed 25 Jun 2025).

<sup>&</sup>lt;sup>96</sup> Indecon, 'The Cost of Disability in Ireland', <a href="https://assets.gov.ie/static/documents/the-cost-of-disability-in-ireland-research-report.pdf">https://assets.gov.ie/static/documents/the-cost-of-disability-in-ireland-research-report.pdf</a> (accessed 26 Jun 2025)

<sup>&</sup>lt;sup>97</sup> Economic and Social Social Research Institute, 'Deprived children in Ireland: Characterising those who are deprived but not income-poor', <a href="https://www.esri.ie/system/files/publications/RS217.pdf">https://www.esri.ie/system/files/publications/RS217.pdf</a> accessed 27 Jun 2025.

<sup>98</sup> 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)

- These Households need an income increase of between 52% 59% to achieve the same standard of living as households with non-Disabled family members;
- Households with a Disabled member with high support needs need an up to 93% income increase to achieve the same standard of living;<sup>99</sup>
- Disabled people face additional costs of between €488 and €555 per week (€25,376-€28,860 per year);<sup>100</sup>
- The at risk of poverty rate is higher for Disabled people 24%, compared to 10% for non-Disabled people.
- When the Cost of Disability is factored in, 65%-76% of Disabled people were at risk of poverty.<sup>101</sup>

The current Disability Allowance rate of €244 per week<sup>102</sup> is inadequate to meet the needs of Autistic and Disabled people. This rate fails to reflect the true cost of living as a Disabled person, especially when accounting for the cumulative impact of low income, limited access to essential services and supports, and the State's fragmented approach to addressing both the Cost of Disability and the structural barriers that Disabled people face in daily life. Payments such as Disability Allowance do not provide enough financial support to live independently within the community – although the payments cover day-to-day expenses, they do not support Autistic people to participate in their community.

<sup>&</sup>lt;sup>99</sup> ECONOMIC AND SOCIAL RESEARCH INSTITUTE, 'Adjusting Estimates of Poverty for the Cost of Disability', <a href="https://www.ihrec.ie/app/uploads/2025/03/Adjusting-Estimates-of-Poverty-for-the-Cost-of-Disability.pdf">https://www.ihrec.ie//app/uploads/2025/03/Adjusting-Estimates-of-Poverty-for-the-Cost-of-Disability.pdf</a> (accessed 26 Jun 2025)

<sup>&</sup>lt;sup>100</sup> 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)

<sup>&</sup>lt;sup>101</sup> 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)

<sup>&</sup>lt;sup>102</sup> Government of Ireland, 'Disability Allowance' <a href="https://www.gov.ie/en/department-of-social-protection/services/disability-allowance/">https://www.gov.ie/en/department-of-social-protection/services/disability-allowance/</a> (accessed 07 Jul 2025).

While the Government has made small annual payments in recent Budgets to address the Cost of Disability, these measures do not meaningfully alleviate financial hardship for most Autistic and Disabled people. The *Programme for Government* committed to introducing a universal Cost of Disability payment, but to date, no clear details have been provided on how it will be implemented. 103

Social protection systems remain difficult to navigate, particularly for Autistic people and our wider community. Community members frequently report that the bureaucratic nature, means testing, and intrusive eligibility processes leave them feeling distressed, humiliated, and retraumatised. Many feel that they were not treated with dignity, but with suspicion at every stage, and fee demonised rather than supported by the social protection system. 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.

#### A Strategic Response to Addressing Disability Poverty

There is a lack of a coherent strategy to address these issues, and to reduce poverty rates

– whilst a successor to the Roadmap for Social Inclusion is being developed, the next

Strategy needs to take a more comprehensive approach to ensure more Autistic people

and Disabled people can make ends meet. Recent reform proposals on disability social

protection payments attracted criticism for focusing on a person's "capacity to work" 104,

<sup>&</sup>lt;sup>103</sup> Government of Ireland, 'Programme for Government 2025 Securing Ireland's Future', p. 100, https://assets.gov.ie/static/documents/programme-for-government-securing-irelands-future.pdf (accessed 07 Jul 2025).

<sup>&</sup>lt;sup>104</sup> Department of Social Protection, 'Green Paper on Disability Reform – A Public Consultation to Reform Disability Payments in Ireland', <a href="https://assets.gov.ie/static/documents/disability-green-paper.pdf">https://assets.gov.ie/static/documents/disability-green-paper.pdf</a> (accessed 07 Jul 2025)

and the proposal to introduce tiered payments did not comply with Ireland's obligations under Article 28 UNCRPD.

#### **Suggested Questions**

- How does the State plan to address the additional Costs of Disability experienced by
  Disabled people and their families, and what measures will be introduced to support
  households in meeting disability-related expenses?
- How does the State plan to reduce poverty among Disabled people and Autistic people?

### Article 31: Statistics and data collection

Ireland lacks a comprehensive system for collecting disaggregated disability-related data. This hinders how we understand and address the barriers faced by Autistic people and Disabled people — particularly for cohorts who face multiple or intersecting forms of discrimination and exclusion. A key example of this is that our Census does not capture data relating to autism, including how many Autistic people are living in Ireland, and this makes it more difficult for the Autistic community to identify issues and support which meet their needs, and advance equality, inclusion and participation.

Under Article 31, the State also must make sure that data is accessible to both policymakers and Autistic and Disabled people. Access to this information supports organisations and communities to participate in decision-making and policy development. However, the State provides no information in its initial State Party Report on how they make data accessible to Disabled people or how disability equality indicators will be

developed in accordance with the UNCRPD. For example, there is currently a two-tier system in education data collection in Ireland. While the State collects extensive data on the outcomes and achievements of children in mainstream schools, there is a significant lack of equivalent data for children attending special schools or autism classes.

# **Suggested Questions**

- What measures is the State party taking to ensure the systematic collection and use of disability-related data disaggregated by sex, gender, ethnicity, and age and type of difference or disability?
- How will Ireland capture data relating to Autistic people for future policy development?
- When will Ireland begin collecting data on school-leavers from special schools, including information on their educational outcomes and the effectiveness of their experiences in these settings?
- How should the State ensure the development of disability equality indicators that align with the CRPD?