



October 2026

**AsI Am Submission to the Department of Children, Disability and Equality on their
Public Consultation to Inform the Review of the *Disability Act 2005***

AsI Am, Ireland's Autism Charity, welcomes the opportunity to send a submission to the Department of Children, Disability and Equality on their Public Consultation to inform the review of the *Disability Act 2005*. Considering both recent issues that affect our community and recent policy developments which align more closely with a rights-based understanding of disability, including the *National Human Rights Strategy for Disabled People*. AsI Am believes that this a timely opportunity to highlight key issues within the current Act and how a future Disability Act would give expression to the full and equal rights of Disabled people under the *United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)*.

This review comes at a critical juncture for disability rights in Ireland – the legal and policy landscape on disability has shifted significantly in the twenty-one years since the Act was enacted. Crucially, Ireland has ratified the UNCRPD and the Optional Protocol to the Convention, offering a rights-based framework with which disability law and policy in Ireland must operate. This also takes place against a backdrop where the Government is making significant changes to our national disability policy, including the rollout of the *National Human Rights Strategy for Disabled People*, the implementation of the *Education for Persons with Special Educational Needs Act 2004*, and wider efforts to strengthen Ireland's implementation of the UNCRPD in areas including disability services.

AsI Am believes that this review should both amend individual provisions of the 2005 Act and reconstitute Ireland's primary legislation on disability within a disability rights framework, creating enforceable rights that realise the right of Disabled people to live as full and equal citizens within Irish society. The University of Galway report *The Disability Act 2005 at 21: Reflecting, Reforming, Reimagining* makes the case for this approach in its analysis of the impact of the Disability Act. The Report states that the current legislation operates a middle ground setting out statutory duties, including the

Assessment of Need, but does not create a right to support that helps Disabled people access services. This is significant for Autistic people and families – as the Autistic community experiences barriers across the life course, particularly in areas under the Act’s remit like education, health and social care, employment, and access to public services. Addressing these barriers means that the core of the Act should recognise Disabled people as rights holders and place clear, legally enforceable duties on the State to vindicate their right to dignity, autonomy and to full and equal participation. As one community member who responded to our *Same Chance Survey* noted, they want “*action not just words and pamphlets.*”

The review marks an important inflection point in Ireland’s approach to disability policy. While there is a more comprehensive policy framework than when the Disability Act was commenced, the everyday living experiences of Autistic and Disabled people show that significant policy gaps. AsIAM’s *Same Chance Report* portrays a stark picture of the barriers faced by the Autistic community. Based on the experiences of 1,676 Autistic people and family members, the Report found that 57% believed there had been little or no progress towards building an Autism-Affirming Society, the stated aim of the *Autism Innovation Strategy*.

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 [here](#).

Recommendations

AsIAM recommends that the review of the Disability Act 2005 should result in a substantial modernisation of Ireland's disability rights framework, rather than a series of isolated technical amendments. The revised framework should be aligned with the UN Convention on the Rights of Persons with Disabilities (UNCRPD), place Disabled people at the centre of decision-making, and establish clear rights, duties, accountability mechanisms and routes to effective remedy.

1. A Rights-Based *Disability Act*

- Reform the *Disability Act 2005* to establish a modern, coherent and enforceable disability rights legislation aligned with the UNCRPD.
- Incorporate the [guiding principles](#) of the UNCRPD throughout the legislation.
- Establish clear statutory duties on public bodies to progressively realise the rights of Disabled people, supported by measurable objectives, implementation plans, monitoring and public reporting.
- Ensure that the legislation recognises disability rights as a whole-of-government responsibility, building on the work of the [National Human Rights Strategy for Disabled People](#).
- Require the meaningful and resourced participation of Disabled people and their representative Disabled Persons Organisations (DPOs) in the development, implementation, monitoring and review of disability legislation and policy, in accordance with Article 4(3) of the UNCRPD.

2. A Consistent Definition of Disability

- Introduce a consistent, rights-based definition of disability aligned with Article 1 of the UNCRPD and reflecting the interaction between impairment and environmental, social and attitudinal barriers.
- Ensure that the definition recognises physical, sensory, intellectual, cognitive, psychosocial and neurodevelopmental disabilities, including non-apparent disabilities.
- Ensure that recognition of a person as Disabled, and their enjoyment of disability rights, does not depend solely on a medical diagnosis or on demonstrating a particular level of functional impairment.
- Distinguish clearly between the definition of disability and eligibility criteria for individual services or supports, so that service-specific thresholds do not determine whether a person is recognised as Disabled or entitled to equality and accessibility protections.

3. Assessment of Need

- Retain the statutory right to an Assessment of Need while substantially reforming Part 2 to ensure that assessments are timely, meaningful, comprehensive and rights-based.
- Establish a statutory right for Disabled adults to access timely and comprehensive assessments of their support needs, linked to clear public-body responsibilities and an effective pathway to appropriate supports.
- Strengthen the enforceability of statutory assessment timeframes and establish effective and accessible remedies where these timeframes are not met.
- Ensure that an Assessment of Need is not treated as an administrative endpoint, but forms part of a pathway through which identified needs lead to appropriate supports, services and reasonable accommodations.
- Ensure that assessments identify the person's health, communication, educational, social and developmental needs, as well as the environmental and attitudinal barriers that affect their participation.
- Ensure assessments are person-centred, multidisciplinary and, where appropriate, informed by relevant expertise in autism and other specific disabilities, using rights-based and neuro-affirmative approaches.
- Ensure that children's rights, evolving capacities, autonomy, participation and informed consent are central to the assessment process, with information provided in accessible formats.
- Prevent reforms to Assessment of Need from introducing higher or narrower eligibility thresholds or mechanisms that restrict access to comprehensive assessment.
- Require transparent national reporting on Assessment of Need waiting times, completion rates, outcomes and unmet needs.
- Address workforce and service capacity alongside legislative reform so that statutory rights can be delivered in practice.

4. Accessibility of Services and Universal Design

- Strengthen Part 3 to establish a comprehensive statutory right to accessible public services and environments, aligned with Article 9 of the UNCRPD.
- Define accessibility broadly to include physical, sensory, communication, information, digital, organisational and attitudinal accessibility.
- Place Universal Design at the centre of public service design and delivery, so that accessibility is incorporated from the outset rather than addressed only through individual accommodation.

- Require public bodies to provide information and communication in accessible and understandable formats, including plain English, Easy Read, alternative formats and appropriate communication supports.
- Strengthen statutory requirements for accessible digital services, websites, applications and other public-facing technologies.
- Embed accessibility and Universal Design requirements within public procurement, commissioning, funding and service-design processes.
- Introduce clearer standards, timeframes, monitoring and reporting requirements for public bodies to meet their accessibility requirements, supported by effective mechanisms for addressing persistent non-compliance.
- Ensure that accessibility duties apply consistently across public services, including healthcare, education, transport, social protection, employment and community services, rather than operating through fragmented sectoral approaches.

5. Employment and Participation in Public Life

- Reform Part 5 so that public sector disability employment policy moves beyond numerical targets towards meaningful recruitment, retention, progression and participation of Disabled employees.
- Require public bodies to ensure that recruitment and promotion processes are accessible, including application processes, interviews, assessments and workplace induction.
- Strengthen requirements for timely, effective and individualised reasonable accommodation throughout recruitment and employment.
- Require public bodies to monitor disability employment data across recruitment, retention, promotion, professional development and career progression, while respecting privacy and data-protection requirements.
- Ensure that Disabled employees have accessible and effective routes to raise concerns, seek workplace accommodations and challenge discrimination.
- Require appropriate training and organisational development to improve disability equality and accessibility across public sector workplaces.

6. A Dedicated Disability Ombudsman

- Establish a dedicated Disability Ombudsman, providing an accessible and independent mechanism for Disabled people to raise concerns about public services and the implementation of disability rights, similar to the Optional Protocol.
- Give the Disability Ombudsman jurisdiction to investigate both individual complaints and systemic issues, including persistent failures in accessibility,

reasonable accommodation, service delivery, administration and implementation of statutory duties.

- Ensure that the complaints process is accessible, free of unnecessary procedural barriers and capable of providing reasonable accommodation and alternative communication methods.
- Provide appropriate powers to obtain information, investigate systemic failures, make recommendations and monitor the implementation of recommendations, with consideration given to stronger consequences for persistent or systemic non-compliance.
- Establish clear relationships between the Disability Ombudsman and the Ombudsman, NDA, CEUD, IHREC, WRC and relevant professional and sectoral bodies, including appropriate referral and information-sharing arrangements.

7. National Disability Authority and Centre for Excellence in Universal Design

- Strengthen the statutory role and resources of the National Disability Authority (NDA) to monitor implementation of disability rights, identify systemic barriers and provide independent advice and public reporting on progress.
- Strengthen the statutory role of the Centre for Excellence in Universal Design (CEUD) in embedding Universal Design across the built environment, digital services, information and communication, procurement, transport and public service design.
- Ensure that NDA and CEUD monitoring, guidance, standards and policy development are informed by the meaningful participation of Disabled people and DPOs and are supported by clear mechanisms for Government and public bodies to respond to identified failures.
- Reform the NDA's governance arrangements to provide for at least 50% representation of Disabled people on its Board, supported by transparent appointments and meaningful representation of the diversity of the Disabled population.

8. National Autism Strategy and Coherent Disability Rights Architecture

Alongside the 40 core recommendations above, AsIAM recommends that the revised legislation establish a clear basis for a **National Autism Strategy**, requiring:

- a whole-of-Government Strategy;
- measurable actions, responsibilities and implementation timelines;
- appropriate resources and transparent progress reporting;
- meaningful participation of Autistic people and DPOs;

- consideration of diversity and intersectionality within the Autistic population;
and
- independent monitoring and review.

The National Autism Strategy should complement, rather than replace, a general disability rights framework: the legislation should establish universal rights and duties, while the Strategy should address autism-specific barriers and coordinate implementation across Government.

Context behind the *Disability Act 2005*

The *Disability Act 2005* was developed in a different legal policy and social context from that which exists today. When the Act was introduced, it represented an important milestone in Ireland's approach to disability. It sought to develop a more structured approach to delivering supports and was presented as a significant step forward in addressing the deep-rooted segregation and marginalisation of Disabled people in many facets of Irish society.

The Act brought together some important measures within a single legislative framework. These included the Assessment of Need and Service Statement process under Part 2, obligations concerning access to public buildings and services under Part 3, protections relating to genetic testing under Part 4, measures concerning the employment of Disabled people in the public sector under Part 5, and the establishment of the Centre for Excellence in Universal Design under Part 6. However, the Act ended up taking a piecemeal approach to combining these procedures and statutory duties, and many Disabled people and families felt frustrated that the Act did not create an enforceable framework of disability rights, which was recommended by the Commission on the Status of People with Disabilities in their Report '*A Strategy for Equality*'.

One important aspect is that the Disability Act significantly predates Ireland's ratification of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). Ireland's ratification of the UNCRPD in 2018 has created a 'paradigm shift' in how Disabled people are perceived in domestic law and policy, recognising them as rights-holders rather than objects of welfare or charity or recipients of services.

Other developments have occurred which have helped shift the legal and policy landscape which the Disability Act operates. The European Union also ratified the UNCRPD and has developed their own strategies to tackle the exclusion of Disabled people across the Union, including the *European Disability Strategy*, the *European Pillar of Social Rights* and the *EU Anti-Poverty Strategy*. Public awareness of the barriers faced by Disabled and Autistic people has been growing in recent years, and there is greater understanding that the root cause of the barriers they face lies with inaccessible environments, services and persistent public attitudes towards disability. The expectations of Disabled people have also evolved. As the University of Galway report observes, the legal environment in which the Act operates today is not the legal environment of 2005.

A key issue identified with how the current Act is structured is that it creates tensions between a system which has been primarily tasked with administering services and the rights-based approach to disability within the UNCRPD. In particular, the Act does not

establish an enforceable right to disability services, instead relying on a “grace and favour” approach. This has significant implications on Disabled people’s wellbeing and living standards, as a statutory process which identifies a person’s needs, but does not create an enforceable obligation to provide timely access to the necessary supports. This creates a deepening gap between rights recognised in legislation and how these rights are realised in people’s day-to-day lives. These tensions are particularly illustrated by the longstanding delays and deepening waiting lists that Autistic people and families face within the Assessment of Need process. Whilst Autistic people and families expect that their Autistic child will receive access to supports like speech and language therapy and occupational therapy, the reality on the ground is families are now waiting at least two years or even longer to get supports.

AsIAM believes that this is an important starting point for reviewing the Disability Act. Whilst the Disability Act was a product of its time and needs to be updated to bring its provisions into line with the UNCRPD, the review provides an opportunity to develop the foundations set by the 2005 Act and substantively address the barriers that Disabled people and families experience on the ground and reimagine Ireland’s approach to disability rights. A rights-based Disability Act should give meaningful effect to Ireland’s obligations under the UNCRPD and ensure that Disabled people are recognised as rights-holders, with clear and enforceable rights, accessible routes to redress, meaningful participation in decisions affecting them, and effective accountability where those rights are not realised.

A key question with this Review lies with both how the Disability Act can be built upon, and what kind of legislative framework is needed to ensure that the full and equal rights of Disabled people are realised in Ireland. Twenty-one years following the *Disability Act*, and considering Ireland’s obligations under the UNCRPD, this is an opportunity to reform and reimagine Ireland’s approach to disability rights.

Aligning the *Disability Act*'s Definition of Disability with the UNCRPD

A key issue for review of the *Disability Act 2005* is the definition of disability itself, as it determines who the State officially recognises as Disabled and is therefore entitled to the rights, supports and legal protections enshrined within Irish law. It also has significant implications for how disability is understood and supported across the breadth of Irish public policy. The UNCRPD reflects a significant change to this, moving away from approaches which locate disability primarily within an individual and towards a human rights and social model which recognises that disability results from the interaction between persons' impairments, and the social, attitudinal and environmental barriers that shape their experience living in society.

Article 1 of the UNCRPD recognises that persons with disabilities include those who have “*long-term physical, mental, intellectual or sensory impairments*” which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others. This understanding should provide the foundation for the definition of disability within a revised Disability Act.

The University of Galway report *The Disability Act 2005 at 21: Reflecting, Reforming, Reimagining* identifies the alignment of the Act with the UNCRPD as a central consideration for reform. It highlights the need for the statutory framework to reflect a contemporary human rights understanding of disability, including autonomy, participation, equality and non-discrimination.

A consistent definition of Disability

AsIAm believes that there is a need to develop a consistent, rights-based understanding of disability across Irish law and public policy. Currently, different legislative frameworks, including in key areas like education and employment, can apply different definitions, thresholds, and approaches to identifying a person's disability and delivering supports. This can result in people being recognised as having a disability in one area of their lives, whilst they may be denied support or encounter barriers in another.

A revised Disability Act should establish a clear definition of disability that is aligned with Article 1 of the UNCRPD, providing a common foundation for disability policy across Government. Where different legislation requires additional eligibility criteria for a particular entitlement or service, these should be clearly distinguished from the underlying definition of disability itself.

Access to a particular service or support may depend on a person's individual circumstances and support needs. However, this should not require a person to

demonstrate that they are sufficiently Disabled or Autistic to have their rights recognised or to access appropriate supports or undermine them as rights holders.

Aligning the Definition of Disability with the UNCRPD

AsIAm recommends that the definition of disability used in a future *Disability Act* should be expressly aligned with Article 1 of the UNCRPD and interpreted consistently with the Convention as a whole.

We believe that the definition of disability should:

- Recognise disability in line with the Social Model and human rights model of disability, where the disability arises through the interaction between the person's differences or impairments, and social, environmental and attitudinal barriers.
- Encompass physical, sensory, intellectual, cognitive and psychosocial disabilities (mental health difficulties), including Neurodiversity and disabilities associated with neurodevelopmental differences.
- Recognise that disability may not always be immediately apparent.
- Avoid relying solely on medical diagnosis or assessments of functional limitation;
- Recognise the importance of barriers to participation, communication, accessibility and equality;
- Be sufficiently flexible to reflect the evolving understanding of disability under international human rights law; and
- Be interpreted in a manner consistent with the principles of autonomy, dignity, equality, non-discrimination, participation and inclusion.

This is important for Autistic people, whose experiences have been consistently viewed through a medicalised or deficit-based lens. Barriers experienced by Autistic people can arise from having to navigate inaccessible environments, barriers to communication, stigma, inflexible system and a lack of access to reasonable accommodations. Some of the persistent stereotypes that Autistic people have to experience include that they do not “*look or seem Autistic*”, that they “*lack empathy*”, “*have no emotions*” or that it was “*just a trend*” and they would “*age out*” of being Autistic. A rights-based definition would better reflect these experiences and provides a more appropriate foundation for understanding disability and the obligations of the State.

Disability should not be reduced to whether a person is eligible for supports

The definition of disability should also be clearly distinguished from criteria used for individual services or supports. Recognition as a Disabled person should not be contingent on an assessment of need. These assessments should not determine whether a person is entitled to the protections within human rights and equality legislation.

This distinction is particularly important in the context of the Assessment of Need process. As highlighted in the University of Galway report, the current framework can create a gap between the existence of a statutory process or entitlement and the practical realisation of rights. As one community member highlighted: *“It is pointless to offer autism diagnosis without supports post diagnosis.”*

A future Disability Act should therefore establish a clear distinction between recognising a person’s disability, any assessment of their individual support needs, and the processes for any services or supports they may be entitled to. This would provide a stronger foundation for a rights-based system in which Disabled people are recognised as rights holders, while individual assessments are used to identify the supports and reasonable accommodations required to enable people to exercise their rights on an equal basis with others.

Setting the foundation for a rights-based Disability Act

The review should use the UNCRPD definition as the starting point for a revised statutory definition of disability and examine how this definition can provide greater consistency across Irish legislation and public policy.

The revised definition should be more than an update to terminology used within the existing Act. It should also reflect the broader shift from a medical and service-led understanding of disability towards a human rights-based framework in which Disabled people are recognised as rights holders and the State has corresponding obligations to remove barriers, prevent discrimination and enable Disabled people’s full and effective participation in all aspects of society.

Part 2: Reforming the Assessment of Need Process

The Assessment of Need (AON) process is a particularly significant element of the *Disability Act 2005* for Autistic and Disabled children. It provides an important statutory mechanism through which a child's disability and support needs can be formally identified, and as a pathway to accessing any therapeutic supports they need.

Part 2 of the *Disability Act* established a statutory Assessment of Need process (AON) for children with disabilities. This represented an important recognition of the right of Disabled children to have their disability and support needs formally assessed. However, significant shortcomings persist in both the operation of the AON process and what happens after a child is assessed and their needs are identified.

The current statutory framework requires an AON to commence within three months of an application and to be completed within a further three months, six months in total. In practice, these statutory timeframes are routinely breached. One community member stated that *"We are still waiting on supports 9 years later in Ireland."* Another notes that the AON process was *"... like being dropped into a maze and trying to find your way around the maze..."* AsIAM's submission to the Joint Committee on Disability Matters highlighted that more than 90% of children waiting for an AON were not seen within the six-month statutory timeframe, with the average waiting period exceeding 27 months and more than 20,000 children overdue an assessment as of December 2025.

These delays cannot be understood as just an administrative issue. For many children and families, an AON is an important route through which support needs are identified and access to services is considered. Prolonged delays can consequently delay access to the supports a child needs to participate in school and their community, health and development, and exercise their rights on an equal basis with other children. This can cause considerable anxiety and distress for children and families, particularly where they are already more likely experiencing barriers to participation and their overall wellbeing than non-Disabled or Neurotypical children. This is reflected in AsIAM's *Same Chance Report*, where 81% of respondents identified long or unpredictable waiting times as a barrier to accessing public services, whereas 70% of respondents reported that they faced barriers to accessing public services.

This is particularly concerning considering Ireland's obligations under the UNCRPD and the UN Convention on the Rights of the Child (UNCRC). [Article 7 of the UNCRPD](#) requires children with disabilities to enjoy their human rights and fundamental freedoms on an equal basis with other children. [Article 25](#) recognises that Disabled people *"have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability"*, while [Article 26](#) requires access to habilitation and rehabilitation services *"to enable persons with disabilities to attain and*

maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life". This includes that access to disability services begin at the earliest possible stage, based on the multidisciplinary assessment of the person's strengths and needs, support their wider participation in the community, and can be accessed locally. A rights-based AON process should therefore identify a child's support needs as early as possible and facilitate timely access to the supports required, while respecting the child's dignity, autonomy and evolving capacities.

Moving from Assessment to Support

A key weakness within the current system lies with the gap between having a right to an Assessment of Need and accessing the supports identified through that Assessment.

The *Disability Act* creates a right to assessment but does not provide a corresponding enforceable right to the timely provision of services identified through it. As a result, a child may receive confirmation of their support needs without having a realistic or timely pathway to access the supports needed to meet these needs. One community member spoke to these barriers: *"Assessment carried out 12 years ago. Given a vague report with a list of services and told my child was on a waiting list. In those 12 years we never got access to any services despite my child's AON saying immediate access to services."*

In 2020 the HSE introduced a Standard Operating Procedure (SOP) which gave effect to the Preliminary Team Assessment (PTA). The Preliminary Team Assessment (PTA) was a controversial 2020 initiative, consisting of a 1-hour observation and 30-minute parent consultation, designed to replace comprehensive diagnostic assessments for children's disability needs. This was introduced to mitigate against the ever-growing waitlist for the Assessment of Need. A High Court ruling in March 2022 deemed the PTA non-compliant with the primary *Disability Act 2005*, forcing a return to a more comprehensive, diagnostic-focused assessment process. The Courts in their determination highlighted how the Assessment process was *"integral to how the State discharges its duties to vindicate the rights of children with disabilities"*. It is from this mantra and position the State should be coming from when it comes to an Assessment of Needs.

AsIAm believes that the review should establish stronger legal guarantees linking the child's assessment and the identification of their support needs with the provision of supports. Where an assessment identifies that a child needs supports, clear responsibilities should be placed on public bodies like the HSE or the NCSE. This should be accompanied by clear timelines for responding to the needs identified in the child's Service Statement and effective accountability mechanisms for addressing any breaches to the child's rights, such as failing to provide support. This would move the

system towards a more comprehensive framework in which an assessment contributes to the vindication of the child's rights and compel the State to go further than simply documenting the child's needs at the time they are assessed.

A Comprehensive and Rights-Based Assessment of Need

An Assessment of Need should seek to understand the child as a whole person and identify the supports they need for them to participate and thrive. AsIAM has previously highlighted concerns where the current AON process can place an undue focus on the child's functional capacity, rather than taking a rights-based, holistic approach to understanding the child and their support needs. This is inconsistent with the UNCRPD's understanding of disability highlighted earlier.

The assessment process should therefore be comprehensive, person-centred, multidisciplinary and neuro-affirmative, where appropriate. It should consider a child's health, communication, education, social and developmental needs, alongside any environmental, social and attitudinal barriers that may affect their overall wellbeing.

This is particularly important for Autistic children, as too often the assessment process treats them as having deficits that need to be treated or fixed, consistent with a medicalised approach to autism. An AON should instead identify the supports, any reasonable accommodations or adjustments to services or their environment that support an Autistic child to learn, communicate, participate and develop on an equal basis.

AsIAM has highlighted that a rights-based and neuro-affirmative assessment can support an Autistic person to understand and accept who they are and support their wellbeing and participation. Conversely, retaining an overly restrictive or bureaucratic process can perpetuate families' sense of isolation and undermine their confidence in accessing public services. This wider experience of navigating disability services is reflected in AsIAM's *Same Chance Report*: 72% of respondents had not received information or guidance on how to navigate services and supports, while 67% did not know where to find clear, accessible information about their rights.

Reform Must Not Lower Standards or Further Restrict Children from Accessing Services

The Review must ensure that any attempts to address waiting lists do not dilute the assessment process or place further barriers to children accessing assessments and support.

Previous attempts by Government to address waiting lists have undermined children's rights in practice - The Preliminary Team Assessment (PTA), introduced in 2020, was intended to respond to growing waiting lists but was subsequently found by the High Court to be non-compliant with the *Disability Act*. The Court recognised the AON process as integral to how the State discharges its duties to vindicate the rights of children with disabilities.

The key lesson is that reducing the time taken to assess a child cannot come at the expense of the assessment process, or whether it is sufficiently comprehensive to identify a child's needs. Reform should address the capacity problems underlying waiting lists rather than reducing the assessment itself to meet administrative targets.

Any reform should therefore ensure that:

- access to an AON is not restricted through higher or narrower eligibility thresholds;
- an initial determination cannot prevent a child from accessing a comprehensive or multidisciplinary assessment where this is required;
- assessments are proportionate to the individual child's circumstances and support needs;
- appropriate clinical and professional expertise is available to facilitate the assessment process;
- children and families receive clear and accessible information about the purpose of the assessment, and what to expect;
- the child's dignity, autonomy, participation and evolving capacities are respected throughout the process; and
- assessments identify a child's access and support needs, rather than managing eligibility for limited resources.

Persistent Failures Weaken the Rights of Disabled People

The persistent failure by the HSE to meet statutory AON timeframes is an issue of barriers to implementation, weaknesses in accountability within the system and constraints on capacity arising from pressures on resources. Families should not have to bear the burden of workforce shortages within our health service, lack of service capacity or failures to anticipate and plan where services are most needed. Speaking to these concerns, one community member highlighted: *"No follow-on support for over 5 years, and when finally engaged with CDNT there is no psychologist available."*

The University of Galway report identifies the gap between statutory rights and their practical implementation as a central weakness of the current framework. It highlights

the need for binding timelines, stronger accountability and effective remedies as part of reform.

The revised Act should therefore make AON timeframes more enforceable and provide meaningful and accessible remedies where these are not met. There should also be transparent public reporting on waiting lists, compliance with statutory timeframes and the provision of supports identified through assessments.

However, legislative reform alone cannot address the crisis happening with accessing children's disability services – it must part of a twin-track that is accompanied by workforce planning, recruitment and retention of relevant professionals, and sufficient capacity within Children's Disability Network Teams (CDNTs) and other services including the In-School Therapy Programme. AsIAM has previously highlighted that vacancies within CDNTs contribute to delays in accessing assessments and supports and the need for additional resources to address.

A rights-based framework therefore requires the Government to address legislative reform, service capacity and workforce planning together. Statutory rights cannot be meaningfully realised where the State has neither provided the resources nor capacity necessary to fulfil their obligations.

Extending the Right to Access Assessments to Disabled Adults

The review should consider establishing an explicit statutory right for Autistic and Disabled adults to have their support needs assessed in a timely, comprehensive and person-centred manner, considering that Autistic and Neurodivergent people are increasingly accessing a diagnosis in adulthood, are acquiring an onset disability or may get a disability as an adult. While the current *Disability Act* establishes a statutory Assessment of Need process for children, the revised framework should also address how adults can obtain a meaningful assessment of their needs and the supports required to exercise their rights within our public health system.

An adult assessment framework should recognise that people's support needs may change over a person's lifetime and may arise or become more apparent at different stages. These stages may include during transitions from children's services to adult services, changes in living circumstances, or the loss of informal support, which may cause considerable distress and disruption to the lives of Autistic and Disabled people. Assessments should consider the person's own views, communication and accessibility requirements, living circumstances, and support needs across areas which affect their wellbeing and ability to exercise their rights.

A statutory right to assessment for adults should therefore establish clear responsibilities for relevant public bodies, appropriate timeframes, accessible review and complaints procedures, and a transparent pathway for responding to the needs identified. This must be accompanied by workforce planning and investment in adult

disability and mental health services, including recruitment of healthcare and clinical professionals so that adults can realise this right.

A Rights-Based Assessment Framework

The review of Part 2 provides an opportunity to reconsider the purpose of an Assessment of Need. The objective should not simply be to process assessments more quickly, but to establish a system through which Disabled children have their needs properly understood, their voices respected and included and the supports necessary to exercise their rights identified and provided.

AsIAM believes that the AON process should be timely, comprehensive, holistic, person-centred, neuro-affirmative and enforceable, and should operate as a genuine pathway for Autistic children to access support that meets their needs.

Recommendations:

1. Strengthen the statutory six-month timeframe for completion of an Assessment of Need and provide meaningful and accessible remedies where it is not met.
2. Establish a clear legal relationship between an assessment, the child's identified support needs and the timely provision of appropriate supports, and clear responsibilities for public bodies.
3. Require assessments to be comprehensive, holistic, person-centred and multidisciplinary where appropriate, and consistent with Ireland's obligations under the UNCRPD and UNCRC.
4. Ensure that assessments consider environmental, social, communication and attitudinal barriers that impact the child's wellbeing and participation, rather than focusing solely on the child's functional capacity.
5. Ensure that changes to the *Disability Act* do not introduce higher eligibility thresholds or administrative mechanisms that restrict families from accessing to comprehensive assessment or appropriate support.
6. Provide children and families with clear and accessible information about their rights, the assessment process, its outcome and the supports identified.
7. Embed the child's dignity, autonomy, participation and evolving capacities throughout the assessment and support process.
8. Establish regular transparent monitoring and public reporting of AON waiting lists, compliance with statutory timeframes and the provision of supports identified through assessments.

9. Accompany legislative reform with workforce planning and significantly increase investment in disability services to ensure that Disabled children's statutory rights can be realised in practice.

Part 3: Making Information and Services More Accessible to Disabled People

Part 3 of the *Disability Act 2005* introduced important statutory obligations relating to access to buildings and services, and tasks public bodies with delivering sectoral plans for making their services more accessible. These provisions were a significant step forward at the time and had been identified by Disabled people as the aspect of the 2005 Act that had been most helpful for Disabled people. However, Disabled people also highlighted that disparities in terms of how accessibility plans were monitored and enforced have meant that this has not consistently translated to an enforceable right to accessible services.

AsIAM believes that there is an opportunity for a successor *Disability Act* to move towards an approach where Disabled people can meaningfully exercise their right to access services, information, buildings and public life on an equal basis with others. This means moving beyond just seeing accessibility as a compliance issue for public bodies and recognising this as a core part of supporting Autistic and Disabled people to be full and active citizens within their community. This is particularly important in the context of the UNCRPD, where Article 9 establishes accessibility as a core foundation for Disabled people to live independently and fully participate in society.

A rights-based approach on accessibility within the UNCRPD and in accordance with the principles of Universal Design means both having access to the physical environment and addressing the full range of barriers impeding Disabled people from accessing services. For Autistic people, can also include sensory processing, inaccessible communication or information, barriers to accessing websites and digital services, stigma and negative attitudes and institutional barriers.

An environment or service being accessible to the Autistic community may rely on whether they provide clear information, allow people ample time to process information, offer multiple forms for people to communicate and interact with the environment or service, consider the impact of the sensory environment and offer flexible ways of accessing their services. A service may be physically accessible but remain inaccessible in other areas. Examples of what Autistic people want to see reflected in accessibility criteria in our *Same Chance Report* include “*reduced waiting times, transparent eligibility criteria, and consistent decision-making*”, alongside services that “*recognise masking, anxiety, and sensory overload rather than relying on narrow stereotypes.*”

The findings of this year’s AsIAM’s *Same Chance Report* show the scale of these accessibility barriers. While 58% of respondents did not feel comfortable spending time in public spaces, 81% did not believe their local community offered safe, low-pressure social spaces for Autistic people. Furthermore, 73% reported having been

excluded from activities or events because their support needs were not considered. These experiences highlight the relationship between accessibility and whether Autistic people can feel safe to participate, belong and feel supported to engage in community life on an equal basis.

The Report's findings on public services reinforce these barriers. For example, 77% of respondents did not believe that the social protection system is accessible to Autistic people – which impacts our community's ability to access services in their community. This indicates that an Autistic person's accessibility needs to be considered across the full experience of interacting with a public service, and that it is not just considered as a technical requirement.

Putting Universal Design at the Heart of Creating More Accessible Services

A revised *Disability Act* should place Universal Design at the heart of its accessibility framework. The objective should be to ensure that services, buildings, communications and systems are designed from the outset to be accessible by the widest possible range of people, rather than relying primarily on individual Disabled people to request reasonable accommodations after barriers have already arisen. Speaking to the need to make accessible supports a part of living in the community, one community member highlighted: *“Normalising the accessible services so they aren't stigmatised, and so anyone that needs them can avail of them.”*

Universal design is important for Autistic people, particularly for those with high support needs, as well as Autistic people who may be masking or who are undiagnosed and may not feel comfortable to disclose or share their needs. Barriers that can be created by excessive noises, unpredictable or crowded environments, complex forms, unclear communication and information, and lack of flexibility concerning engagement with services, can make it harder for Autistic people across day-to-day life. Speaking to these concerns, one community member wanted to see *“more autism friendly spaces like quiet spaces or designated times or neurodivergent only activities and spaces.”*

Accessible Information and Communication

Accessibility must also include a clear expectation that public bodies provide information and communication in accessible formats that Autistic and Disabled people can understand and use. This should include consideration of Easy-to-Read, plain English, alternative formats, accessible websites and digital services, appropriate communication supports, Augmentative and Alternative Communication and Irish Sign Language. Accessibility should be built into how public information is designed and communicated throughout. Reflecting these concerns, one community member stated:

“I would love to see an easy read of all the laws, services and supports currently available to autistic people.”

Whilst the Disability Act mainly conceived accessing public services as being mainly face-to-face, this is increasingly taking place through the digital environment where people are using websites, online portals, apps, digital correspondence and other forms of technology to access public services. The Act needs to be updated to reflect this shift and address gaps to accessing information and services online, and to allow Autistic people to access these services online. This is currently within the remit of the National Disability Authority and the Centre for Excellence in Universal Design, which will be covered in more detail in a later section.

Stronger Duties, Monitoring and Enforcement

A central weakness of Part 3 is that obligations imposed on public services have not been accompanied by sufficiently strong mechanisms to ensure compliance. The University of Galway research found that accessibility duties remain subject to weak monitoring and limited sanctions.

The revised Act should therefore establish clear and measurable duties to make environments more accessible, accompanied by appropriate monitoring, reporting and enforcement mechanisms. Public bodies should be required to demonstrate how they are identifying and removing accessibility barriers, rather than relying solely on individual complaints to expose when these gaps occur.

This should include:

- clear and consistent accessibility standards applying across public services and the built, digital and information environments;
- time-bound requirements for addressing identified barriers to accessing environments and services;
- regular public reporting on compliance and progress;
- effective and accessible mechanisms for Disabled people to report barriers and hold public bodies to account;
- appropriate powers for an independent oversight body to investigate when failure to make services accessible occur and hold public bodies to account; and
- meaningful sanctions where public bodies repeatedly fail to meet their statutory obligations.

Accessibility should also be incorporated into public procurement, commissioning and service design, so that inaccessible systems are not created or renewed through public expenditure.

Sectoral Plans and Whole-of-Government Responsibility

The review should also reconsider the role of sectoral plans within Part 3. While sectoral planning was an important feature of the original Act, the University of Galway report identifies this model has been weakening in practice, with disability policy increasingly being pursued through broader cross-Government strategies and structures.

A revised legislative framework should therefore ensure that responsibility for accessibility does not become fragmented between individual Departments or public bodies. Accessibility should be treated as a whole-of-government responsibility, with clear accountability for implementation and measurable outcomes. Many of which featured in the *Autism Innovation Strategy*.

This is particularly important because the barriers experienced by Autistic people frequently cross traditional departmental boundaries. A person may encounter barriers to healthcare, education, transport, social protection, employment and community services as part of the same everyday life. The legal framework should reflect this reality rather and take a life course approach to making services more accessible.

Enshrining the Right to Independent Living in the new *Disability Act*

Article 19 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) recognises the equal right of Disabled people to live independently and to be included in the community. This includes the right to choose where and with whom they live, and to have access to the range of individualised supports, including personal assistance, necessary to facilitate them to live and participate in the community. At its core, the right to independent living for many Autistic people means having the right to live ordinary lives in ordinary places, with dignity, choice, control and access to the supports they need.¹ People may live independently in their own home with support, have access to a Personal Assistant or home support, in supported living arrangements or through other forms of living in the community, depending on their preferences and support needs. These supports should afford Autistic people to exercise as much choice and control as possible and be supported in a way that respects their rights, will and preferences. [General Comment 5 on Article 19 of the UNCRPD](#) offers more details on how States can realise the right to independent living for Disabled people.

AslAm believes that a new *Disability Act* should give meaningful and enforceable effect to the right to independent living. Whilst Ireland has made some important progress towards meeting our obligations to move Disabled people out of congregated settings and into the community, including in the most recent strategy *Time to Move on from Congregated Settings* and the *National Housing Strategy for Disabled People*. However, progress on deinstitutionalisation, which is the process of supporting Disabled people to move out of institutional and congregated settings and into homes in their community, has been slow and piecemeal in practice, where policy commitments have largely fallen short of meeting the needs or reflecting the experiences of Autistic and Disabled people and our wider communities.

AslAm's [Same Chance Report](#) shows the extent to which Autistic people continue to face barriers to independent living and active participation in community life. Among respondents, 72% reported that they did not have the supports they needed to live independently in the community. The Report also found that 81% did not believe that their local community offered safe, low-pressure social spaces, while 73% reported having been excluded from activities or events because their support needs had not been considered. These findings all speak to a more concerning issue that by not supporting Autistic people to live independently, many in our community feel a deep sense of isolation and disconnection from their wider communities. The [Same Chance Report](#) offers further insights into what Autistic people say they need to make independent living a reality – 70% said that needed mental health and wellbeing

¹ Article 19, United Nations Convention on the Rights of Persons with Disabilities, [Article 19 – Living independently and being included in the community | United Nations Enable](#), (accessed 07 Oct 2026)

supports, 47% each said that they wanted more accessible housing and better supports for social inclusion, 46% wanted more options around supported living and housing supports, 45% wanted more support around daily living skills, 41% wanted better support around employment, 30% wanted to access personalised budgets and 28% want better access to personal assistance. Among the 16% of other respondents who identified other supports needed to live independently, many emphasised the importance of financial security, access to housing, and practical day-to-day supports.

In addition to all these barriers, community members also highlighted that having access to consistent supports and information around the supports available around independent living was a key issue, and this did not just stem on having a roof over their head. One respondent described the issue particularly clearly:

“Independent living is not solely about ability but also about access to appropriate services, predictable supports, and environments that accommodate sensory and anxiety-related challenges.”

Another respondent described the importance of recognising that needing support does not diminish a person's independence: *“There is no shame in needing support from your community after all!”*. Financial barriers to accessing housing and independent living supports were frequently highlighted, with several respondents sharing that current rates of social protection supports were not sufficient to fully meet the cost of living independently. One respondent stated that they need *“money to do so,”* while another shared that *“Disability Allowance wouldn’t even cover rent... I have no chances of living alone in the foreseeable future.”* Others highlighted the importance of having ongoing support networks, explaining that even when living independently, they still rely on family or community assistance. One respondent explained that *“I live independently but have family nearby who help me a lot.”* Others raised concerns about personal safety, particularly when living alone, which one respondent stated: *“A lot of it [is] fear. Especially as an Autistic woman. I feel like a vulnerable, easy-to-take-advantage-of person, and I have been taken advantage of many a time.”*

These experiences are all the more important when considering what independent living under Article 19 looks like for Autistic people who have been excluded from these conversations, including Autistic people with higher or more complex support needs, who have cooccurring intellectual disabilities or communication support needs.

Deinstitutionalisation and the right to ordinary lives in ordinary places

Ireland has a longstanding commitment to deinstitutionalisation. The [European Network on Independent Living](#) states that *“Deinstitutionalisation is a political and a social process, which provides for the shift from institutional care and other isolating*

and segregating settings to independent living.”. The [*Time to Move on from Congregated Settings*](#) Report published in 2011, set out a policy direction towards supporting people with disabilities to move from congregated settings into homes in the community, and with Government making a commitment to allocating capital investment to delivering this objective. The Government's current disability capital programme also identifies the need to increase independent living supports and supports for people to live at home, including to address the issue of younger people with disabilities living long-term in nursing homes.

However, progress on deinstitutionalisation has been slow and many Autistic and Disabled people continue to live in settings where their right to dignity, choice, and control over their lives are restricted in real terms. As highlighted in [*AsIAM's Submission to the UNCRPD Committee*](#), as of January 2025 there were 1,249 Disabled people under the age of 65 living in nursing homes in Ireland, with the key reason offered being due to lack of available supports in the community. This reflects the need for deinstitutionalisation to be delivered, and requires both Disabled people making decisions on how they wish to live and access to the supports they need to realise their right to choose where and with whom they wish to live. This is a pressing issue for Autistic people who may have high support needs or require significant support with their communication, their personal care, with decision-making or with everyday activities. The lack of supports that meet the needs of these cohorts in our community means that Autistic people with higher support needs, many of whom may be living with their families, are having to rely on residential services irrespective of whether this reflects their own will and preferences.

Our most recent [*Same Chance Report*](#) puts these concerns into sharp focus. Respondents described that they face a lack of available properties and supports, difficulties navigating what can be a bureaucratic housing system, needing to access supported living or independent living support, and concerns about what will happen when family members who currently provide substantial support are no longer able to do so. Community members described the need for a clear pathway to ensure that their Autistic family member would be supported to live independently when they were no longer able to provide that support:

“Affordable housing for autistic people and pipelines for young adults to find ways to live on their own or in shared homes where their lives can be shaped by their skills and choices, rather than living at home with their parents out of necessity.”

“What happens to our kids when we are no longer here”

“My son will need lifelong care. I'm getting older while he is getting bigger and stronger. I fear for our future”

Planning for the Future and the Weight on Families

The right to independent living is particularly pressing for Autistic and Disabled people who may be relying on aging parents of their families for support. The *Before We Die Campaign* has brought national attention to the consequences of a system in which families can be left without a clear pathway for the future, and these concerns are echoed by many families within our community. The campaign was established by parents of adults with intellectual disabilities around a fundamental question: what will happen to their family member when they are no longer able to provide care? It highlights the risk that, when a family carer becomes ill or dies, a person's housing and support needs can suddenly become an emergency due to a failure in anticipating this need and planning for making this transition. This is at odds with Article 19 of the UNCRPD, and Autistic people and Disabled people, particularly those who need more support, should not have to wait for a crisis to happen or their loved ones can no longer provide this support before any plans around housing and supports, any planning around making this transition are discussed.

The State should also support Autistic people and Disabled people and families to make arrangements and work in partnership with the HSE around clear pathways for housing and supports, including any information they need around making transition planning and opportunities for the person themselves to express their own will and preferences and consider these decisions with their family. This should include the support for families at all stages of the transition and navigating this process.

Legal capacity and independent living

The right to independent living can often go hand-in-hand with Article 12 of the UNCRPD. The Assisted Decision-Making (Capacity) Act 2015, which commenced in 2023, established a rights-based framework for supporting adults who may require assistance to make decisions and replaced the previous Ward of Court system, with a range of decision-making supports. This framework operates on the basis that all Disabled people have capacity and have the right to make decisions about their lives in accordance with their will and preferences. Inclusion Ireland have highlighted the importance of supporting people with intellectual disabilities to make their own decisions, including decisions about housing, finances, healthcare and everyday life. Its work also emphasises the important role that families and trusted supporters can play where this reflects the person's wishes and preferences. This is an important issue for Autistic people with higher support needs as many make the assumption that they are “vulnerable” and not able to live independently because they need more support to communicate, make decisions, manage activities or understand information.

The Right to Personal Assistance

The right to personal assistance is an important mechanism in which Disabled people can exercise the right to independent living. AsIAM's colleagues on the DPO Network, [Independent Living Movement Ireland's](#) (ILMI) work has emphasised the distinction between Personal Assistance and traditional models of care: Personal Assistance places the person themselves directly in control of the supports they want, enabling them to exercise choice and participate in all aspects of their life. ILMI has campaigned for the right to personal assistance and to a national Personal Assistance system based on defining, standardising, investing in, promoting and legislating for PAS.

AsIAM believes that this approach should inform the development of the new *Disability Act*. The Act should recognise that individualised supports may include Personal Assistance, supported living, communication supports, assistive technology, accessible transport, employment supports, respite and family supports, or self-directed funding like personalised budgets. Supports should follow the person rather than expecting them to fit their lives around what disability services offer.

Independent living as a substantive right

AsIAM believes that the new *Disability Act* should give explicit legal effect to the right to independent living and inclusion in the community under Article 19.

This should include statutory duties to:

- ensure that Disabled people have genuine choice and control over where and with whom they live;
- ensure access to appropriate, individualised supports necessary to exercise their right to independent living;
- develop sufficient accessible and affordable community-based housing and supported living;
- accelerate the transition from congregated settings towards ordinary homes in the community;
- prevent people from being placed in nursing homes or remaining in institutional settings because of a lack of appropriate community-based supports;
- establish a clear national pathway for future planning, particularly for people whose current support depends ageing family members;
- provide access to Personal Assistance and other individualised supports, based on the person's support needs, will and preferences;
- develop personalised budgets and self-directed support options;
- ensure that people with high support needs, intellectual disabilities and communication support needs are not excluded from exercising their right to independent living because of the level or extent of their support needs;

- ensure that people receive accessible information about their options around housing and supports;
- ensure that independent advocacy and supported decision-making are available;
- provide appropriate transition planning for young people moving from education and children's services into adult life;
- provide appropriate supports to families and unpaid supporters, while ensuring that family care is not treated as a substitute for State-funded community supports; and
- establish measurable targets, transparent reporting and independent monitoring of progress towards deinstitutionalisation and community inclusion.

Part 4: Genetic Testing and the Impact on Autistic People's Right to Autonomy

One area of the Disability Act that has raised concerns within the Autistic community and we believe should be strengthened through this review is the regulation of genetic testing and its implications for research about autism and the rights and experiences of Autistic people. The Act's existing provisions are important in protecting Autistic and Disabled people from discrimination based on the genetic information they provide. However, the Review must consider whether these provisions are sufficient in light of evolving research on autism, including research led by Autistic researchers and clinical professionals and informed by Autistic people themselves, and growing public understanding of the genetic and hereditary traits associated with autism. The [UK National Autistic Society](#) recently published a statement highlighting that autism is genetic. This review should also consider whether existing safeguards effectively protect Autistic people and adequately address the growing use of Artificial Intelligence (AI), machine-learning and predictive technologies, including their potential to influence the public's understanding of autism and decisions affecting Autistic and Disabled people.

The University of Galway's report on the *Disability Act* found that there were significant gaps in public understanding around the Act's provisions on genetic testing. Of 156 respondents, 59% were unaware that the Act contains provisions regulating genetic testing in employment and insurance, while a further 14% were unsure. Some key reasons highlighted by respondents is concerns that genetic testing would affect their right to privacy and that this information is not accessible to Disabled people, the potential that sensitive medical data would be used to discriminate against them and ethical concerns that this would reinforce medicalised attitudes towards Autistic and Disabled people.

Within the Autistic community, issues around genetic testing has caused considerable concern. For example, the [AIMS-2-TRIALS](#) project was initially paused following a backlash over an initial proposal to collect 10,000 DNA samples from Autistic people. Concerns were raised about the lack of meaningful consultation with the Autistic community regarding the project's aims, as well as fears that data could be misused by researchers seeking to 'cure' autism or promote eugenics or disablist attitudes towards Autistic people.

This has become an even more significant issue for our community as the rapid growth in misinformation around autism is fuelling stigma and harmful stereotypes about Autistic people, and in turn led to policies and supports being developed based on these misconceptions and stereotypes. Our most recent *Same Chance Report* found that 68% of respondents believed that misinformation about autism and Autistic people has increased over the past year, and 91% feeling that the Government was not doing enough to tackle misinformation on autism. This reflects that the spread of

misinformation continues to persist and is becoming a more entrenched and systemic issue, and the difficulties of addressing misinformation once it has taken hold. Some of the reasons community members gave include:

“Taking paracetamol during pregnancy that was a total misinformation and we as a family got told that we caused our son to have autism”

“People discussing autism as something that needs to be cured, as if it was a disease.”

“Minimisation of people's experiences and talk of ‘everyone wants a diagnosis now’.”

“As a female Autistic person, I’ve been met with the response that I don’t fit the typically understood definition of what autism is, and so others have questioned my identifying as Autistic. This is because I heavily rely on masking in social situations, which gives the appearance of someone comfortable in social situations. People’s understanding of autism tends to be narrowly defined as someone who is often outwardly distressed/dysregulated.”

“In my community, autism is often misunderstood as an intellectual disability, or as something that makes a person unable to function in society at all. That misunderstanding is painful. My children are not treated differently because of their needs - they are treated differently because of other people’s biases. Autism is not a sickness, and it is not a measure of intelligence. With the right support, and with inclusion, understanding and grace, our children can live full, capable and meaningful lives.”

These perspectives show that misinformation about autism has led to Autistic people being more isolated, distressed and stigmatised. The Autistic community are particularly concerned that narratives about an “explosion” of autism diagnoses or “overdiagnosis” of autism would be used to justify removing supports or question their experiences of being Autistic. The National Disability Authority’s report [*“Estimating Autism Prevalence in Ireland: Challenges and Opportunities”*](#) found that there was no evidence suggesting that there is an overdiagnosis of autism in Ireland. This speaks to the need for robust evidence to shape public policy around autism in Ireland.

AsIAM calls on the review on the Disability Act to consider where the Disability Act’s provisions on genetic testing can be strengthened to protect Autistic people from discrimination and prevent the misuse of genetic information. This includes considering how genetic data increasingly interacts with predictive models and algorithms used in areas like recruitment, insurance, and potentially within our public services to make decisions impacting Disabled people. Appropriate safeguards are needed to prevent genetic information from being used in ways that disadvantage Disabled people, reinforce discriminatory or negative assumptions or undermine their rights. This also

reflects the need to take a more proactive approach to privacy, handling personal information and providing for the person to give free and informed consent to the use of their personal data in this manner.

Provisions around genetic testing should also reflect a proactive approach from Government to specifically addressing misinformation about autism. Information communicated to the public about genetics and autism should be accurate, evidence-based and developed with meaningful input from Autistic people, relevant researchers and clinical professionals, and representative organisations. This would help advocates and organisations to challenge negative stereotypes about autism but also support researchers to actively involve Autistic people in growing our understanding of autism, ensuring that the science around autism that is communicated to the public is accurate, comes from reliable sources and fully respects the rights and personhood of Autistic people.

Part 5: Employing Autistic and Disabled People within the Public Sector

Part 5 of the *Disability Act* introduced obligations on public bodies in relation to the recruitment and employment of Disabled people, including requirements to promote and support their employment and to meet a statutory minimum recruitment target. These provisions represented a recognition of the State's responsibility to ensure that Disabled people can work in the public sector on an equal basis with others.

However, more than 20 years since the Disability Act was enacted, AslAm believes that Part 5 should be significantly strengthened. The current framework has largely focused on meeting an employment target as opposed to ensuring that Disabled people can access public sector employment, remain in employment, progress in their careers and can fully participate in the workplace. We believe that the revised Disability Act should develop a comprehensive and enforceable framework for promoting autism understanding and acceptance and disability equality and supporting more Autistic and Disabled people to work across the public sector.

For Autistic people, barriers to employment can arise at all stages of their career, including the recruitment process, workplace assessments, communication, navigating workplace cultures and hierarchies, disclosing that they are Autistic or Disabled to their employer, asking for supports or reasonable accommodations at work, retention and career progression. Whilst Part 5 has encouraged Disabled people to apply for roles in the public sector, addressing these barriers more substantively requires public bodies to investigate how their policies, processes and practices may create or reinforces barriers to the workplace for Autistic and Disabled people. As one community member explained: *"I now know that I have a lot of potential to thrive in my chosen field but need to get help in doing so when it comes to accommodations."*

Moving from Employment Targets to Promoting Meaningful Participation

The public sector should lead by example in the recruitment and employment of Autistic and Disabled people. The State is a major employer and is also responsible for implementing Ireland's obligations under the UNCRPD. Article 27 of the UNCRPD states that Ireland has an obligation to ensure that Disabled people have equal right to work, including access to the labour market, recruitment and working conditions, providing equal access to training and advancement, supporting self-employment and entrepreneurship, reasonable accommodations and protection from harassment and discrimination.²

² Article 27, UN Convention on the Rights of Persons with Disabilities, [Article 27 - Work and employment | Division for Inclusive Social Development \(DISD\)](#) (accessed 07 Oct 2026)

The existing public sector recruitment target, which was raised to 6% in the [National Human Rights Strategy for Disabled People](#), has created greater impetus for public bodies to make progress on employing more Disabled people. Whilst this has helped public bodies to be more accountable, this has not meant that workplaces within the public sector are necessarily more equal or neuro-affirmative. Whilst an organisation within the public sector can show that they can meet their recruitment target, Autistic and Disabled people may continue to struggle with key aspects like inaccessible recruitment processes, inadequate reasonable accommodations, limited opportunities for progression or workplace cultures in which people do not feel safe disclosing their disability or where they may be treated differently for being open about being Autistic or Disabled.

The review of Part 5 provides an opportunity to strengthen the statutory duty on public bodies to promote the recruitment, retention and participation of Disabled people. Whilst a key part of compliance should focus on how many Disabled people a public body employs across different levels within their organisation, but it should also focus Disabled people have the same chance to enter, remain with and advance their career through the organisation.

AsIAm believes that the revised Act should establish clear responsibilities for public bodies to:

- recruit and retain Disabled employees;
- ensure recruitment and promotion processes are accessible and neuro-affirmative;
- provide reasonable accommodations in a timely and effective manner;
- identify and remove systemic barriers to employment;
- support career development and progression;
- maintain workplaces in which Disabled employees can raise concerns and advocate for their needs safely and without feeling judged;
- collect and publish disaggregated data on the experiences of Disabled employees;
- have structured policies that support the wellbeing of Disabled employees; and
- demonstrate progress against clear and measurable objectives for supporting Disabled employees and candidates within the public sector.

Ensuring Recruitment and Assessment Processes are Accessible

Recruitment processes can create significant barriers for Autistic and Disabled candidates before they have had an opportunity to show why their skills may be suitable for the role offered. Standardised processes like Application forms, psychometric

testing, workplace assessments, job interviews and other recruitment practices may disadvantage candidates whose communication or processing skills may not be fully supported within a conventional recruitment process.

AsIAM's *Autism in the Workplace* Report found that 96% of Autistic adults felt they would find it more difficult to find the job they want compared with a non-Autistic person. We also found that 58% believed requesting reasonable accommodation would hinder their prospects of securing their preferred role. It is vital for public bodies to ensure that candidates should not have to choose between accessing accommodations for their interview and risk being perceived negatively by a prospective employer by having to go through a process without supports they need.

In AsIAM's most recent *Same Chance Report*, 76% of respondents reported that they required a reasonable accommodation at work or when looking for work, while 69% did not believe that employers in Ireland were becoming more autism-accessible, including in areas such as providing accommodations that meet their sensory needs, flexible working and clear communication. This reflects the need for accessible recruitment to be embedded across the public sector. Autistic candidates should not have to repeatedly justify why they are looking for a particular workplace support or accommodation. Recruitment bodies should proactively consider accessibility when designing application, assessment and interview processes – it is important to highlight to employers that providing reasonable accommodations does not provide an unfair advantage to Disabled candidates and these practices benefit every candidate.

For example, public bodies should consider offering:

- interview questions, themes or topics in advance;
- additional processing time for Autistic candidates;
- alternative methods for candidates to show their skills and competencies;
- clear and accessible information about each stage of the recruitment process;
- clear and actionable feedback after a candidate has completed their interview;
- flexibility in communication methods;
- accessible assessment environments; and
- opportunities for candidates to identify their support needs and the accommodations they wish to access.

Disclosure and Self-Advocacy in the Workplace

For many Disabled employees, access to reasonable accommodations can play a significant factor in determining whether they are able to enter, remain or progress in their chosen career. AsIAM's engagement with our community highlights that it matters a great deal to Autistic employees that they need to be sure that advocating for

themselves would be positively received by employers before making the decision to do so. Autistic adults have often described that they face a dilemma on whether they make the decision to disclose that they are Autistic. They may be concerned that if they ask for support or accommodations, that this would be viewed negatively, and that prevailing workplace attitudes or a lack of understanding of autism may make it more difficult to access supports. They may also be left in a position where they must explain or justify their support needs to access accommodations they are legally entitled to rather than the process being an ongoing conversation with their employer. Some examples of reasonable accommodations for Autistic employees may include adjusting the workplace environment, offering flexible working hours, being allowed to work remotely more days per week, adjusting ways that information is communicated, like using step-by-step instructions. A rights-based approach should not take a prescriptive approach to reasonable accommodation and support employees to identify what supports they need that would help them to thrive at work.

Public bodies should have clear, accessible processes for requesting, agreeing and reviewing reasonable accommodations. Employees should not be required to repeatedly share the same access needs or disclose their disability every time when moving between roles or organisations within the public service or into a public sector role, particularly where they may have the same support needs as they progress in their career. Processes should also recognise that an Autistic employee's access needs can change over time, meaning that reasonable accommodation should be treated as an ongoing part of making employment more accessible and inclusive for every employee.

Promoting Safe and Inclusive Workplaces

An inclusive workplace should support Disabled people to raise any concerns they have with their employers, and advocate for themselves at work without fear, retaliation, ridicule or being treated differently.

AsIAM's engagement with Autistic adults have highlighted that many Autistic people have experienced bullying, harassment and discrimination at work, and have wider concerns about being singled out or being treated differently by being open about their Autistic identity with their employer. There are also concerns that, where Autistic people experience bullying, harassment or discrimination at work, that their complaints may not be taken seriously, investigated or addressed appropriately. These experiences can affect their wellbeing, confidence, self-esteem and job performance, and may discourage Autistic people from disclosing their identity or seeking the reasonable accommodations and supports they need to participate and progress at work.

Changes to Part 5 should recognise that promoting psychological safety at work and fostering inclusive workplace cultures are important aspects of making workplaces

more inclusive for Autistic and Neurodivergent people. This should also include that employees have accessible mechanisms to share their concerns and be protected from discrimination, bullying and harassment and exclusion at work. People working in HR, Management and in workplace relations should have access to disability equality and autism acceptance training, including education on the specific barriers that Autistic and Neurodivergent staff face. Complaints and concerns at work should be treated with sensitivity to the needs of Disabled people and should be a fair, transparent and accessible process.

We take the view that these additional protections would strengthen the employment rights under the *Employment Equality Acts*, shifting the reliance on employees to challenge discrimination as they see it happen and encouraging organisations to proactively make workplaces more inclusive and accessible.

Increasing Career Progression and Representation Across the Public Sector

Whilst the State has made important and welcome progress in increasing the visibility and representation of Disabled people in the public sector, a key challenge is ensuring that Disabled People can see progress with organisations and reach senior and leadership positions. A person-centred public service should provide Disabled employees with equal opportunities to develop their careers, access training, take on leadership responsibilities and progress to more senior roles that reflect their experience, skills and personal qualities. Many Autistic people are motivated to work in the public sector and are committed to being of service, particularly if they are in roles that align with their skills or interests. They should have the same chance to build fulfilling careers where their skills and qualities are recognised and valued.

In our Same Chance Report, we found that 58% have had negative experiences at work or looking for work in the past year, and more concerningly, 85% have said that employers have either partially provided or have not provided the workplace supports they were looking for.

Reflecting the progress made with the *National Human Rights Strategy for Disabled People*, we believe that Part 5 should also focus on supporting the career progression of Disabled people across the public sector, including:

- accessible professional development and training;
- mentoring and career development programmes;
- opportunities for networking and peer support;
- leadership and progression initiatives for Disabled employees;

- flexible working arrangements that support Disabled people throughout their career; and
- effective workplace supports during periods of illness, burnout, fluctuations in energy or changes to their personal circumstances.

Public bodies should monitor whether Disabled employees are progressing with their organisations and feel supported in their roles, with the aim of seeing greater representation of Disabled people in leadership roles across all grades. As part of the reporting process, organisations should explain if there are significant barriers to retention and progression and work with Disabled people to address them.

Collecting Disaggregated Data on Employment Outcomes

Part 5 provides the opportunity to strengthen the collection of disaggregated data across the employment lifecycle. This should include data relating to recruitment, retention, promotion, requests for reasonable accommodation and career progression across different cohorts within the Disabled community. Data should be appropriately disaggregated so that patterns affecting Disabled employees can be identified and addressed. The Autism Innovation Strategy includes commitments to improve equality data relating to Autistic people and to use this information to inform recruitment practices and workplace policies. A revised Disability Act should provide a stronger legislative framework through which such commitments can be sustained and monitored that support Disabled people over their career. This will assist us to build a more complete picture of their experiences working in the public sector, and for Autistic employees, help shine a light on what is working and where further support is needed.

The Public Sector as a Role Model for the Wider Workforce

Finally, Part 5 should build a vision for the public sector that both increases disability and neurodiversity representation, and where Disabled people are supported to build sustainable careers, pursue their interests and aspirations and feel that they belong and accepted for who they are.

This reflects the direction of travel established by the *National Human Rights Strategy for Disabled People 2025–2030*. Under the Employment pillar, the Strategy makes commitments to:

Maximise opportunities for Disabled people to secure work across the civil and public service, alongside measure to promote their recruitment and career progression in the private sector, expanding mentoring, and inclusive recruitment practices.

The review of Part 5 offers an opportunity to build a stronger statutory basis for these commitments, and place greater responsibility on public bodies to build better workplaces that reflect our values as a society.

Greater representation of Disabled people across the public service, including in professional, senior and leadership positions, can also challenge assumptions and negative stereotypes about disability and demonstrate that Disabled people are valued contributors to public life and active citizens. Greater representation of Autistic people across the workforce can help challenge negative stereotypes about what Autistic people can contribute to within the workforce.

Role of the Ombudsman's Office and Making the Case for a dedicated Disability Ombudsman

The Office of the Ombudsman plays an important role in protecting people from unfair treatment and discrimination from public bodies and has a number of specific functions under the *Disability Act*. Under Part 3, the Ombudsman can investigate complaints concerning access to public buildings, services and information, as well as complaints relating to sectoral plans. This provides an important complaints mechanism for Disabled people where a public body has not met their obligations under the Act, particularly as the Ombudsman can investigate complaints concerning the rights of Disabled people under its remit.

The Ombudsman has recently undertaken work investigating systemic barriers faced by Disabled people and showing the importance of independent oversight in practice. This includes “Grounded”, which highlighted barriers to equal access to personal transport schemes, reports examining the Motorised Transport Scheme and school transport for Disabled children. “Wasted Lives” documented the experiences of young Disabled people who are inappropriately placed in nursing homes.

However, the Ombudsman’s role and powers do not fully reflect the scale of barriers faced by Autistic and Disabled people, particularly where they face barriers in areas like education or disability services. In relation to Part 3 complaints, a person generally must first raise their complaint with the relevant public body and, an internal Inquiry Officer appointed by that body will investigate the complaint before the matter can be brought to the Ombudsman. The Ombudsman's role under the Disability Act is also principally confined to Part 3. It does not extend to public sector employment under Part 5, while other disability-related rights and complaints may fall within the remit of other bodies, including the Irish Human Rights and Equality Commission, the Workplace Relations Commission or other sectoral complaints mechanisms like CORU. A person generally must first raise their complaint with the relevant public body and, in relation to Part 3 complaints, an internal Inquiry Officer appointed by that body will investigate the complaint before the matter can be brought to the Ombudsman. This creates a fragmented structure where access to different mechanisms may depend on which service a Disabled person and their family are using, the nature of the right concerned and the legislation under which the complaint arises. For a Disabled person who is already experiencing significant barriers to accessing public services and essential supports, having to navigate multiple complaints and oversight mechanisms can create an additional barrier to vindicating their rights. This fragmentation can make it more difficult for individuals to hold the State to account and to exercise, in practice, their right to seek redress under the Optional Protocol to the UNCRPD.

Making the Case for a dedicated Disability Ombudsman

As part of the review of the Disability Act, AsIAM believes that there is a strong case for establishing a dedicated Disability Ombudsman within a stronger rights-based framework. This could potentially provide a clear and accessible route for Disabled people and their families to ensure that public bodies uphold their rights and promote greater public awareness and understanding of disability rights in Ireland.

This Disability Ombudsman should also be able to provide an independent route for resolving individual complaints whilst also identifying systemic shortcomings and work in concert with the National Disability Authority in providing advice and recommendations for reform. It should have the expertise and powers to investigate whether public bodies are meeting their obligations under the *Disability Act* and under the UNCRPD. Disabled people and their families should not be expected to be legal experts or have intimate knowledge of the role different public bodies play to vindicate their rights.

Investigating Complaints and Laying the Groundwork for Structural Reform

A strong Disability Ombudsman should at an individual level, be able to investigate complaints concerning failures by public bodies to meet their obligations under the revised Act, including accessibility around environments and public services, failures to provide reasonable accommodations, accessible information and communication, and other statutory duties that fall under disability and equality legislation.

At a systemic level, the Ombudsman should be able to identify where recurring or widespread failures happen with public bodies and make recommendations addressing the root causes of these issues. This could include examining patterns where services are inaccessible, where people face persistent bureaucratic hurdles when navigating public services, where services and public persistently fail to provide reasonable accommodations, or the persistent delays in the provision of supports.

This would complement the work of other statutory bodies. The Irish Human Rights and Equality Commission, Workplace Relations Commission and other relevant bodies like the National Disability Authority would retain their existing functions within their respective mandates. The objective should be to lay the groundwork for a clearer and more coherent disability rights architecture.

A Disability Ombudsman should be Independent

A dedicated Disability Ombudsman should have a clear mandate, be independent and have sufficient resources to discharge its functions. Its powers should include the ability to investigate complaints, obtain relevant information, make recommendations

for individual redress and systemic change, monitor responses to recommendations, and report publicly on recurring or significant failures.

Consideration should also be given to whether the Ombudsman should have stronger powers or enforcement and accountability than currently available under the Disability Act, particularly in relation to where organisations are persistently found to be non-compliant with the Act's provisions. Any such powers should be proportionate and subject to appropriate safeguards, but the revised framework should ensure that independent oversight can lead to meaningful change rather than simply identifying that a failure has occurred.

The Ombudsman should also have a proactive role in promoting awareness of disability rights and supporting public bodies to understand their legal obligations, taking a more ambitious remit from just addressing individual complaints after a breach has occurred towards supporting public bodies to proactively prevent systemic barriers from impacting Disabled people's day-to-day lives.

A Disability Ombudsman as Part of a Wider Disability Rights Framework

A dedicated Disability Ombudsman should not be a substitute for enforceable rights or for ineffective legislation that fails to create the clear statutory duties, rights and entitlements and legal remedies necessary to meaningfully support Disabled People.

The Ombudsman should be part of a clear disability rights structure that is consistent with the UNCRPD where clear statutory duties, accessible complaints mechanisms, independent monitoring, effective remedies, appropriate judicial or quasi-judicial oversight, and meaningful participation of Disabled people and Disabled Persons Organisations all work to progressively realise the rights of Disabled people in real terms. The revised Act should establish a clear relationship between the Disability Ombudsman, the National Disability Authority, the Centre for Excellence in Universal Design, the Irish Human Rights and Equality Commission and other statutory oversight and complaints bodies, including CORU and the NCSE. This would help ensure that Disabled people have a clear mechanism for addressing breaches to their rights.

Role of the National Disability Authority and Centre for Excellence for Universal Design

The National Disability Authority (NDA) has a crucial role in supporting the development of disability policy in Ireland. As the independent statutory body providing expert advice to the Government on disability policy and advising the Government on key decisions, the NDA supports the State to meet its obligations under the UNCRPD and in promoting the inclusion and participation of Disabled people.

The Centre for Excellence in Universal Design (CEUD), within the NDA, has a complementary role in promoting Universal Design and supporting the development of environments, products, services and systems that can be accessed, understood and used by the widest possible range of people across Irish society. Together, the NDA and CEUD provide valuable expertise that should be central to the implementation of a disability rights framework in Ireland. This submission previously discussed the importance of Universal Design for the Autistic community in accessing buildings and services and feeling included in their community.

The review of the Disability Act allows us the opportunity to reflect on whether the bodies, powers and resources of both bodies meet the ambitions of building a disability rights framework that is consistent with our obligations under the UNCRPD. Both bodies were established before Ireland ratified the UNCRPD, while Universal Design has become increasingly important to the way public services, environments and systems are designed and delivered, including for Autistic people. A revised legislative framework could potentially consider how the NDA and CEUD can be strengthened to support the progressive realisation of disability rights in Ireland.

Strengthening the National Disability Authority

The NDA should have a stronger and more public-facing role in monitoring the implementation of the revised Disability Act and Ireland's wider disability rights obligations. It should have an expanded role in both advising Government on individual legislation and policy. It should also assess whether the State is making progress on removing barriers and realising the rights of Disabled people.

A strengthened NDA could have a clearer statutory role in:

- monitoring implementation of the revised Disability Act and relevant national disability strategies like the *National Human Rights Strategy for Disabled People*;
- advising Government and public bodies on compliance with the UNCRPD;
- developing indicators and benchmarks against which progress can be measured;

- collecting, analysing and publishing data on disability equality and participation;
- reviewing the implementation of statutory duties and identifying structural barriers that impact Disabled people;
- reporting publicly on progress and areas where further action is required;
- supporting public bodies to develop effective disability equality policies and practices; and
- facilitating meaningful participation by Disabled people and DPOs in the development, implementation and monitoring of disability policy.

This would strengthen the NDA's remit and expertise on disability, while also supporting greater accountability for Government Departments and public bodies in implementing their statutory obligations.

Strengthening the Representation of Disabled People in the Governance of the National Disability Authority

Considering the importance of the NDA's role in advising Government on disability policy, supporting the monitoring and implementation of the UNCRPD and on disability rights, its role and governance may also reflect the principle that Disabled people must be centrally involved in decisions that affect their lives.

In reviewing the Disability Act, we would take the view that the Government should reform the NDA's governance requirements to require that 50% of its Board members are Disabled people for future Boards. This would help ensure that lived experience is represented at the highest level of decision-making, complementing the NDA's policy and research expertise and strengthening its accountability to Disabled community.

This requirement should be supported by transparent appointment procedures and measures to promote greater diversity among Board members, including representation of people with different disabilities, support needs, identities and lived experiences. Disabled people's representation should be meaningful and should not replace the NDA's wider obligations to consult and work in partnership with Disabled Persons' Organisations (DPOs).

Addressing the Gap between Policy and Implementation

A key challenge in disability policy in Ireland is addressing the gap between policy commitments and implementation. Ireland often described as “policy rich, implementation poor”, with a significant and growing body of disability strategies and action and implementation plans but these do not consistently translate into meaningful improvements in Disabled people's day-to-day experiences.

The revised Disability Act should consider whether the NDA should have stronger mechanisms for monitoring implementation and drawing public attention to persistent breaches of Disabled people's rights to the Government, the Oireachtas and the wider public. This could include regular reporting on public bodies' progress in meeting their statutory duties, reviews into the causes of these structural issues and powers to make recommendations to address persistent issues when public bodies continually fail to meet their obligations. The NDA has done very effective work over the past few years including conducting research and policy advice to Government within the Autism Innovation Strategy under its current remit. A new *Disability Act* presents opportunities for the NDA to align Ireland more closely with the UNCPRD. It also presents opportunities to facilitate the delivery of more substantive reforms that help to build a more accessible and inclusive society, for both Autistic people and other disabled people, and for everyone living in Irish society.

Within its remit, it can provide independent expertise and oversight and raise public awareness on disability rights and the issues that affect Disabled people. This would mean that whilst Government and public bodies are responsible for making decisions concerning how our public services are delivered, making them accessible and ensuring the rights of Disabled people are reflected in Government decisions.

Enhancing the Centre for Excellence in Universal Design

The Centre for Excellence helps to support Ireland's transition to encouraging more public bodies to consider making services universally accessible from the outset. Any revisions to the Disability Act should strengthen Universal Design as a core part of public policy and delivering services to the public. This should of course include making buildings and physical environments accessible, but also all aspects of where citizens engage with services – including digital services, information and communication, transport, procurement, public services and the design of policies and administrative processes. Many Autistic people tell us that while a service provided by the State can be physically accessible, they may become distressed when navigating crowded settings, overwhelming sensory environments, information that can be difficult to process, lack of predictability and wider systemic and communication barriers. These barriers can be compounded when people with cooccurring disabilities access public services.

Universal Design therefore needs to anticipate and address a wide range of physical, sensory, cognitive, communication and neurodevelopmental differences from the design stage and throughout. This should reduce the need for individual Disabled people to request accommodations after these barriers have already arisen.

CEUD should have a stronger statutory role in supporting public bodies to apply Universal Design consistently. This could include:

- developing and maintaining standards and guidance for Universal Design;
- advising on the design and procurement of public services, buildings, information and digital systems;
- supporting public bodies to incorporate Universal Design at the earliest stages of policy and service development;
- developing accessibility and Universal Design indicators against which public bodies can assess performance;
- supporting training and capacity-building across the public service;
- undertaking research and identifying emerging accessibility barriers;
- supporting innovation in accessible and inclusive service design; and
- working with Disabled people and DPOs to ensure that Universal Design standards reflect lived experience.

We believe that strengthening the CEUD's role would help to ensure that Universal Design is embedded more coherently across Government and our public services, coordinating the public sector to proactively design services, buildings and online platforms which are accessible from the ground up.

Participation of Disabled People and DPOs

The strengthening of the NDA and CEUD should also be accompanied by a clear commitment to support the meaningful participation of Disabled people and DPOs in research, co-production and policy advice and supporting underrepresented communities to participate. Many within the Autistic community perceive that policies which shape how they live in Irish society do not always necessarily reflect their living experiences or what they want to address about living in Irish society. There are opportunities for the NDA to build on this progress by both proactively consulting the community on key policies and to push for greater representation in forums where these decisions are made.

Expertise in disability policy and Universal Design should be complemented with lived experience. Article 4(3) of the UNCRPD requires States to closely consult with and actively involve Disabled people, through their representative organisations, in the development and implementation of laws and policies concerning them.

Disabled people and DPOs should therefore have a meaningful role in shaping the NDA's monitoring priorities, the development of Universal Design standards and guidance highlighting best practice, and the monitoring of these standards.

Participation should be appropriately resourced, accessible and be a consistent process where their expertise can inform the NDA's policy advice to Government and public bodies. The importance of lived experience and participation is also evident in the Autistic community's own expectations of policy and service development. One respondent explained that *"we want to benefit from the experience of autistic people and their families."* Another community member stated, *"Advocacy, consultation, and*

decision-making processes need to be genuinely accessible, practical, and responsive to the realities of autistic individuals and families.”

The revised *Disability Act* should establish a clearer relationship between the NDA, CEUD and the other bodies responsible for disability equality, human rights, accessibility and complaints. Clear roles and referral mechanisms would help ensuring that there is consistent accountability between institutions and that findings from complaints, inspections, research and monitoring can inform wider policy and practice.

The National Autism Strategy and the Disability Act

Ireland's first *Autism Innovation Strategy* was introduced in 2024, which marked a sea change in autism policy. The Strategy set out a cross-Government approach to addressing barriers faced by Autistic people and included 83 actions across Government Departments and State agencies. The Strategy was grounded in rights-focused, person-centred and neuro-affirmative principles and recognised the need to improve access to public services, develop more accessible and inclusive communities, and build capacity within the Autistic community.

However the Strategy was set out as a time limited programme of work, and we were concerned that this progress was not underpinned by legislation requiring the Government to regularly publish a *National Autism Strategy*. AsIAM has previously raised concerns that if the Government did not legislate for an Autism Strategy, there is every chance that progress made by the Autism Innovation Strategy would not be sustained or built upon, and the barriers our community face would further deepen. In our submission to the UNCRPD Committee's List of Issues process for Ireland, AsIAM called for a successor National Autism Strategy to be developed and co-produced with our community and underpinned by legislation, consistent with the Government's commitment in the Programme for Government.

AsIAM's most recent Same Chance Report shows the importance that the Autistic community places on a *National Autism Strategy*, arguing that the current *Autism Innovation Strategy* “*must not be a one-off programme of work, but an ongoing process that needs sustained and consistent resourcing, monitoring and implementation*”. 96% of respondents believe that the Government should legislate for a National Autism Strategy. The report also found that 99% believe that a future National Autism Strategy should include post-diagnostic supports. Respondents highlighted the need for greater collaboration with the Autistic community in designing and implementing public services, as well as more accessible services, more consistent supports for Autistic people and families across all parts of Ireland, shorter waiting times and easier access to assessments and follow-on supports.

These findings reinforce our view that a National Autism Strategy should provide a long-term framework for addressing the barriers faced by Autistic people and families across the life course in health, education, employment, poverty and social exclusion, housing, transport, public services and living in the community. The experience of the Autism Innovation Strategy demonstrates the value of coordinated action across Government, but also the importance of ensuring that this action is sustained, adequately resourced and subject to meaningful monitoring and accountability in partnership with Autistic people.

How a new *National Autism Strategy* would promote an Autism-affirming society

AsIAm recommends that the Government legislate for a *National Autism Strategy* for Ireland to build on the current *Autism Innovation Strategy* and provide a longer-term framework to more comprehensively support the Autistic community. The *Autism Innovation Strategy* is an important first step in coordinating actions across Government. However, its time-bound nature means that many supports and initiatives risk losing momentum once the Strategy ends. To avoid a cliff edge and ensure that the Government continues to support the Autistic community into the future, we believe that the current Strategy should be extended, whilst a new *National Autism Strategy* is developed and legislated for.

Legislating for a *National Autism Strategy* would place policies supporting Autistic people on a statutory footing and ensure that Government Departments and State agencies have clear responsibilities for delivering support and are more accountable to the Autistic community. It would also ensure that any progress under the *Autism Innovation Strategy* is strengthened and sustained over time. Crucially, many of the priorities identified through engagement with our community reflect on calls for Government to expand commitments within the current *Autism Innovation Strategy*, highlighting that the current Strategy must not be a one-off programme of work, but an ongoing process that needs sustained and consistent resourcing, monitoring and implementation.

A *National Autism Strategy* also sits within the overarching framework of disability policy under the *National Human Rights Strategy for Disabled People*. These strategies should be mutually reinforcing: the National Human Rights Strategy should advance the rights of Disabled people generally, while a National Autism Strategy should coordinate action on the specific barriers and support needs experienced by Autistic people.

The review of the *Disability Act 2005* should consider the most appropriate legislative mechanism for delivering this commitment. This could involve establishing a statutory basis for a *National Autism Strategy* within a revised Disability Act or introducing dedicated standalone legislation.

A future *National Autism Strategy* should be co-designed with Autistic people and their representative organisations, in accordance with Article 4(3) of the UNCRPD. It should reflect the diversity of Autistic people's experiences and address barriers across the life course, including access to assessment and post-diagnostic supports, education, healthcare, employment, housing, independent living, social protection, public services and community participation.

Crucially, the Strategy should set out a coordinated programme of action to promote an Autism-affirming society. Priorities identified by the Autistic community should include:

- Deliver national public information and education campaigns that reflect the diversity of Autistic experiences and challenge outdated assumptions and negative stereotypes about autism.
- Develop a coordinated Government response to address misinformation and disinformation about autism seen online, in public debate and in media coverage, particularly claims that reinforce harmful narratives or stereotypes about autism.
- Work in partnership with media organisations and with Coimisiún na Meán to ensure that portrayals of Autistic people reflect the diversity of Autistic people's experiences.
- Develop approaches for meaningful participation of Autistic people in public conversations about autism, including media engagement, public campaigns and greater engagement in national policy development.
- Mandate the use of neuro-affirmative language across public services, education and media so that autism is understood as part of neurodiversity and as a key part of policies supporting Disabled people.
- Introduce autism and neurodiversity education in schools and strengthen training for professionals across healthcare, education, employment services and the wider public sector.

Comparative International Legislation

To fully consider a review of the Disability Act 2005, it is useful to examine comparable legislation and policy frameworks in other jurisdictions. This section considers several approaches to the provision of disability rights internationally, including the extent to which the UNCRPD is reflected in relevant legislative and policy frameworks. It also considers the definitions of disability adopted in some of these frameworks and highlights examples of the enforcement, oversight and accountability mechanisms that have been identified in the jurisdictions examined.

The United Kingdom ratified the UNCRPD in 2009, together with its Optional Protocol, which enables individuals and groups to submit communications to the UN Committee on the Rights of Persons with Disabilities after domestic remedies have been exhausted³. The UNCRPD has not, however, been incorporated into UK domestic law as a whole. Instead, disability rights are addressed through a combination of different legislative Acts, including Equality Act 2010 and the Disability Discrimination Act (DDA) 1995 in Northern Ireland. Additionally, Scotland has incorporated the United Nations Convention on the Rights of the Child (UNCRC) into domestic law in 2024. This includes the rights of disabled children to accountability across public services⁴.

The Equality Act 2010 sets out protection from discrimination on several grounds including the discrimination of disabled people⁵. This Act applies to England, Scotland and Wales⁶, and establishes protection from discrimination across a number of areas including employment, education and the provision of goods and services. Northern Ireland has a separate legislative framework for disability rights, the Disability Discrimination Act 1995, which prohibits discrimination against disabled people in areas including access to goods and services and in property and land transactions, education, and public transport. The framework is overseen and enforced by the Equality Commission for Northern Ireland, which has statutory functions in relation to equality and discrimination laws. This was further strengthened in 2006 by an Order in Council, which extended the coverage of the Act and increased its scope to include more recognised disabilities. The Order also provided that all trains would have to be fully accessible by 2020. While discrimination in education was covered by existing legislation, additional rights for disabled students were prescribed through the Special Educational Needs and Disability Act 2001, which applied to England and Wales; the

³ <https://researchbriefings.files.parliament.uk/documents/CBP-7367/CBP-7367.pdf>

⁴ <https://www.gov.scot/publications/national-transitions-adulthood-strategy-young-disabled-people-supplementary-report/pages/3/>

⁵ <https://www.gov.uk/rights-disabled-person>

⁶ https://onlinelibrary.wiley.com/doi/pdfdirect/10.1111/1460-6984.70098?utm_source=consensus

Education (Additional Support for Learning) Act 2004 in Scotland; and the Special Educational Needs and Disability Order 2005 in Northern Ireland.

The definition of disability covered in the DDA1995 takes a medical approach, stating that a person is considered disabled “*if he has a physical or mental impairment which has a substantial and long-term adverse effect on his ability to carry out normal day-to-day activities*”⁷. The definition in the Equality Act 2010 largely retains this approach. However, official guidance documents attempt to provide greater clarity on what is meant by the definition. The guidance provides further explanation of what is meant by an impairment, and particularly the terms “substantial”, “long-term”, “adverse effect” and “normal day-to-day activities”. It also lists autism as an “impairment” and, therefore, as a disability protected under the Act⁵. In terms of enforcement, under the Equality 2010 Act the UK’s Equality and Human Rights Commission⁸ serve to enforce The Equality Act 2010 in England Scotland and Wales, in a role similar to that of the Equality Commission of Northern Ireland⁹.

Across the UK, specific legislation has been introduced aimed at providing for the rights of Autistic people. England introduced the Autism Act 2009, while Northern Ireland subsequently introduced the Autism Act (Northern Ireland) 2011. Wales has taken a different approach through its Statutory Code of Practice on the Delivery of Autism Services, which provides a specific framework for the delivery of autism services. Despite these developments, concerns have been raised about the extent to which the rights provided for in legislation are realised in practice¹⁰. This demonstrates the importance of examining not only the legislative framework itself, but also the extent to which it delivers meaningful rights and protections in practice. Scotland has taken a further approach through the proposed Learning Disabilities, Autism and Neurodivergence (LDAN) Bill, which seeks to address learning disabilities, Autism and other forms of Neurodivergence through specific legislation. While the progression of the Bill has been halted in favour of policy reforms¹¹, the continued development of proposals demonstrates an ongoing support from the Autistic community and

⁷ Equality Act 2010 Guidance, available:

https://assets.publishing.service.gov.uk/media/5a80dcc8ed915d74e6230df4/Equality_Act_2010-disability_definition.pdf

⁸ [Inquiries and investigations | EHRC](#)

⁹ [Disability | Equality Commission NI](#)

¹⁰ **Not Enough:** [Not Enough](#)

Social Policy Association: <https://social-policy.org.uk/spa-blog/blog-autism-education-in-wales-and-northern-ireland-why-promises-still-fall-short/>

¹¹ Bloomer, A. (2026) ‘Scottish Government abandons Learning Disabilities, Autism and Neurodivergence (LDAN) Bill’, *Learning Disability Today*, 09 Sep, available:

<https://www.learningdisabilitytoday.co.uk/news/scottish-government-abandons-learning-disabilities-autism-and-neurodivergence-ldan-bill/>

campaigners for specific legislation that is appropriate to address the rights and needs of Autistic people and other Neurodivergent people.

Norway has taken a more comprehensive, rights-based approach to the rights of disabled people by incorporating the UNCRPD into domestic law through its Human Rights Act earlier this year. This was described as a historic step forward by campaigners, advocates and the wider disabled community¹². By incorporating the UNCRPD, the Human Rights Act adopts the Convention's definition of a disability, which is firmly rooted in the social and human rights models of disability.

The incorporation of the UNCRPD gives the Convention a higher level of legal protection within Norwegian law, including precedence over other legislation where a conflict arises¹³. "*Courts, public authorities and municipalities will be required to use CRPD directly when interpreting rights and making decisions*"¹⁴. In practice, the Convention can therefore be relied upon directly in decision-making and appeals concerning the rights of disabled people, including where decisions fail to adequately consider accommodation needs. Advocates have also emphasised that the UNCRPD should be considered by municipalities in the processing of cases concerning people with disabilities, even where existing legislation is considered broadly consistent with the Convention¹⁵.

As with the UK, however, campaigners have emphasised that legislative and legal protections must be accompanied by effective implementation in practice. While the incorporation of the UNCRPD represents a significant step in strengthening the legal protection of disabled people's rights, advocates have highlighted "*real change will depend on political will, training, awareness, and pressure from civil society*"¹⁶.

The examples considered highlight both the potential benefits and the limitations of different approaches, including the importance of how legislation is implemented, monitored and enforced in practice. There is scope for greater cross-border cooperation and learning between Ireland and Northern Ireland. Despite operating within different legislative frameworks, the shared geographical context and similarities in the issues faced by disabled people on both sides of the border provide an opportunity "*to not only facilitate smoother implementation of both models but also to lay the foundation for developing larger, long-term collaboration in cross-border healthcare*"¹⁷. The

¹² [Norway Makes History - ENIL](#)

¹³ [CRPD i norsk lov– om rettigheter og saksbehandling - Løvemammaene](#)

¹⁴ <https://enil.eu/norway-makes-history/>

¹⁵ [CRPD i norsk lov– om rettigheter og saksbehandling - Løvemammaene](#)

¹⁶ [Norway Makes History - ENIL](#)

¹⁷ O'Mahony, C. (2024) 'A comparative analysis of the intersection of mental capacity laws and international human rights law in Northern Ireland and Ireland', *Northern Ireland Legal Quarterly*, Vol. 75 No. 4 (2024) 753–789, available: [View of A comparative analysis of the intersection of mental capacity laws and international human rights law in Northern Ireland and Ireland](#)

international examples also demonstrate an opportunity for Ireland to take a leading approach to disability rights through the review of the Disability Act 2005. Ireland can use this review to position itself as a champion of disability and human rights and to contribute to setting a higher standard for the protection and realisation of disabled people's rights on the international stage. It also provides an opportunity to consider whether the legislative framework adequately reflects a social and human rights model of disability and whether it provides an effective basis for the full realisation of disabled people's rights in practice.

Additional Rights and Cross-Cutting Issues the Government Should Consider for the Disability Act

A rights-based approach to the Disability Act in line with the UNCRPD needs to also recognise that legislation should also address cross-cutting issues that impact Autistic and Disabled people's ability to exercise their rights. These include a greater recognition of intersectionality throughout the Act, as well as access to justice, data collection and meaningful participation in engagement processes.

Intersectionality

The revised legislative framework should explicitly recognise the role intersectionality plays in shaping the Autistic and Disabled community's experiences and address the multiple and often overlapping forms of discrimination and disadvantage experienced by many Autistic and Disabled people. Disability does not exist in a vacuum and people's experience of being Autistic or Disabled can often be shaped by their gender, age, ethnicity, socioeconomic status, sexual orientation, gender identity, family circumstances and in other ways. These may create distinct barriers for Autistic and Disabled people to access services, exercising their rights and freedoms as citizens, participating in community life and the right to freedom from violence or abuse.

The framework should therefore require public bodies to consider these intersecting inequalities when developing policies, delivering services, making decisions and assessing the impact of legislation. This obligation should apply across all relevant rights covered by legislation, including accessibility, independent living, family life, education, employment, healthcare, safety and community participation.

The legislation should also recognise the diversity of the Disabled population, including people with intellectual disabilities, psychosocial disabilities or mental health difficulties, neurodivergent people and people with high or complex support needs. A rights-based framework must ensure that no person is excluded from exercising their rights because their support needs are significant, their communication differs from what people expect like using AAC devices or they experience multiple forms of discrimination.

Access to Justice

The Disability Act also needs to establish accessible and effective routes through which Disabled people can assert their rights and hold public bodies accountable when their rights are breached. This should include accessible complaints procedures, transparent and timely decision-making, independent advocacy, appropriate communication supports, accessible information about their rights and entitlements,

and effective mechanisms for reviewing decisions and addressing systemic failures. Where necessary, people should be able to access monitoring and regulatory bodies who have powers to investigate complaints and appropriate judicial or other legal remedies. Vindicating the right to access justice means that Disabled people should be able to understand their rights, navigate administrative processes, challenge decisions and obtain support without encountering further barriers because of the very disability-related or structural barriers that have contributed to the original problem.

The legislation should establish clear responsibilities for public bodies, alongside effective mechanisms for monitoring compliance and addressing breaches to the rights of Disabled people that fall within their remit. Any independent oversight or complaints body should complement, rather than replace, enforceable rights and access to the courts. The precise institutional model should be determined through a properly informed and participatory review of existing mechanisms, their powers and their effectiveness.

Disaggregated Data and Accountability

The revised framework should establish clear obligations for the collection, publication and use of accurate, accessible and appropriately disaggregated data to inform disability policy and monitor the realisation of rights.

Government departments and relevant public bodies should collect and share data, subject to appropriate privacy and data-protection safeguards, to identify inequalities in access to services, supports and opportunities. Where feasible and appropriate, data should be disaggregated by disability, gender, age, ethnicity and other relevant characteristics, as well as support needs and geographical area to help identify otherwise unseen barriers.

Data collection should be informed by Disabled people and their representative organisations, with appropriate safeguards to ensure that people are not reduced to medical diagnoses or deficit-based measures. Quantitative data should be complemented by qualitative data highlighting the lived experiences of Disabled people.

Crucially, this data should be collected merely for reporting, as well as inform implementation, how resources are allocated, how services are planned and delivered and whether public bodies are fulfilling their statutory duties. Public bodies should be required to report transparently on progress against defined objectives and timelines, identify gaps in implementation and explain what steps they will take to address them.

Meaningful Participation and Ongoing Review

Every issue is a disability rights issue and issues affecting Disabled people affect everyone in Ireland. The revised framework should establish a clear and continuing obligation to involve Disabled people and their representative organisations in decisions that affect their rights. This should reflect Article 4(3) of the UNCRPD and the principle that Disabled people must be actively involved in the development and implementation of laws and policies that concerning them.

Participation must be meaningful, accessible and adequately resourced. It include formal consultation processes, but the Government also needs to include Disabled people in ongoing engagement in policy development, implementation, monitoring and review, and make these processes accessible and understandable. Public bodies should provide Disabled people with accessible information, appropriate communication supports and allow sufficient time for participation and for DPOs to consult their membership, while ensuring that Disabled Persons Organisations have the capacity to contribute independently and effectively.

The current review should be the beginning of a sustained process where our primary legislation for disability evolves to meet the needs of our community. The Government should establish an ongoing, properly resourced structure through which Disabled people and their representative organisations can help shape this future legislation, assess different ways of changing the Act and for monitoring how it is implemented.

Progressive Realisation of Rights through the *Disability Act*

The revised framework should ensure that financial and administrative issues do not become a blanket justification for failing to advance Disabled people's rights. Where rights are subject to progressive realisation under the UNCRPD, this must involve deliberate, concrete and targeted steps towards their full implementation, using the available resources to progress these rights effectively.

Legislation should require public bodies to set clear objectives, establish timelines, monitor progress and explain how resources are being used to fulfil their obligations. Any limitations or delays should be transparent, properly justified and subject to scrutiny. The concept of progressive realisation must not be interpreted as permission to postpone action indefinitely or to leave Disabled people without essential supports while systemic barriers persist.

At the same time, the framework should distinguish between rights that require immediate protection and obligations whose full implementation may require delivering these rights over time. This distinction should be informed by our own obligations under the UNCRPD.