June 2022

AsIAm Autism Innovation Strategy Submission

Message from our CEO

AsIAm are delighted to make a submission as part of the consultative process for the forthcoming Autism Innovation Strategy. As an organisation, we have long campaigned for the creation of a National Autism Strategy, with an associated legislative basis, and we see this process and the work of the new Joint Oireachtas Committee on Autism as key steps forward in this regard.

At least 1 in 65 people in Ireland are Autistic and whilst public awareness of Autism has risen greatly in recent years, it remains that Autistic people face barriers in society not experienced by other people. These barriers emerge across the life cycle and indeed every aspect of Irish life – from accessing timely diagnosis and supports, to securing a school place or finding a job, through to making friends, accessing healthcare, or accessing public services. Statistically, and from the testimony of Autistic people and our families, our community does not enjoy the same chance in Ireland of 2022. It has long been highlighted that there is a need to create a more joint-up approach to supporting our community across Government as well as recognising that in order to bring about true equality both access to appropriate supports and a culture change in terms of public attitudes and the accessibility of Irish society are critical to building a more just and inclusive society for Autistic people and our families. We believe an innovative Strategy, led by the Department of Children, Equality, Disability, Integration and Youth, can go some way towards achieving these goals.

In drafting our submission, we have consulted extensively with the Autism community – hosting four focus groups and circulating a survey which received more than 400 responses. What we propose in response to the questions posted by the Department's Consultation Document are reflective of the breadth of experiences and priorities from across our diverse community. As the Strategy process continues, our organisation is committed to facilitating further consultation as required and remains available to support the drafting and implementation of the Strategy in any way we can.

We welcome the efforts which have been made to-date to ensure the accessibility of the consultation process and the proposed oversight structures which will support the sign-off and implementation of the Strategy. The centrality of the voice of Autistic people and families in this process is to be welcomed and is critical in terms of meeting Ireland’s obligations under the United Nations Convention on the Rights of Persons with Disabilities. As we eagerly await the drafting and publication of Ireland’s first Autism Innovation Strategy, we are reminded that all too often our community has been left disappointed. Impressive legislation and strategic documents have too often failed to be followed by effective implementation, appropriate resourcing or measurable outcomes and impact. It is vital that we see the creation of the Strategy as just step one in meeting the urgent needs of Ireland’s Autistic community.

Every good wish,

Adam Harris

Founder-CEO – AsIAm

About AsIAm

AsIAm is Ireland’s National Autism Charity. We are working to create a society in which every Autistic person is empowered to reach their own personal potential and to fully participate in society. Our purpose is to advocate for an inclusive society for Autistic people that is accessible, accepting and affirming._We work to support the Autistic community and our families to fully engage in Irish life and build the capacity of society to facilitate true inclusion.

Our organisation has made its mark on the national landscape since our founding in 2014, from our award-winning campaigns to lobbying lawmakers to prioritise the experiences of Autistic people on the Oireachtas’ agenda. AsIAm has developed a range of supports for Ireland’s Autism community; as well as providing vital information and advocacy supports, we have also delivered several nationally and internationally renowned training and accreditation programmes for businesses and services to become accessible for Autistic people.

Key Actions for Consideration

The below list provides a summary of the key actions and recommendations for consideration which we explore throughout our submission in further detail:

Access to Services and Supports

- Ensure that all Autistic children and adults have access to appropriate services and supports. Timely access to key services and supports, in tandem with urgently reducing excessive waiting times for services must be a priority of this strategy.
- Roll out mandatory Training for all public sector workers including targeted training opportunities for those working closely with Autistic people in the education, health, social protection, housing, and criminal justice sectors
- Enhanced measures to support Autistic people accessing public transport
- Recognition by government of relevant ID cards and self-advocacy supports which enable Autistic people to access support in community settings.
- A programme to promote the accessibility of public services for those using Assisted Augmented Communication (AAC) and access to training for AAC for public services and members of the public
- Better data collecting, including having a reference to Autism in Ireland's next census. Access to data, will allow for better planning and forecasting in relation to services.
- Review of initial training and CPD requirements for relevant professions to ensure all those working with Autistic people have the required knowledge
- Access to support workers and personal assistants for Autistic adults and legislate for the Right to Personal Assistance for people with disabilities.

Ensuring an Accessible, Appropriate Education for Every Autistic Person

- Conduct an Independent review of the quality of education provision for Autistic people.
- Reform of the Summer Programme to ensure all Autistic people who wish to access the programme are enabled to do so.
- Develop and promote the use of targeted on-campus supports for Autistic people in Further Education

- Develop bespoke programmes which support Autistic people in accessing relationships and sexuality education.
- Creating an inclusive education system can only come to fruition with better planning/central data base of information, which would ensure no child is without an appropriate school place or the supports needed to access an education in their local school.
- Providing training to primary, secondary school and third level students nationwide on Understanding Autism, accepting and including Autistic people.
- Abolish the use of inappropriate sanctions such as expulsion, suspensions, and non-agreed reduced timetables for Autistic students, in mainstream classes, Autism classes and special schools, experiencing distress
- Roll out training based on a rights-based approach to understanding and accepting Autistic person for teachers and all professionals across all levels of the education system.
- Promote the use of Universal Design for Learning (UDL) in teacher training and in designing future primary, second and third level curricula
- Expansion of access to the Middletown Centre for Autism Pilot Programme for young autistic people in need of wrap around support within the education system.

Ensuring Equal Access to Healthcare and Promoting Wellbeing of Autistic People and Families

- Based on our experience of the COVID-19 pandemic put in place appropriate procedures to ensure the needs of Autistic people are properly planned for in the response to future national emergencies.
- Measures to improve the accessibility of healthcare for Autistic people
- Targeted supports for Autistic people accessing pre-natal and post-natal care
- Roll-out of training for counsellors and mental health professionals on supporting autistic clients
- The appropriate regulation of the advertising and delivery of therapies, including the development of a Code of Ethics, to ensure that therapies used

are person-centred, rights based and affirm the Autistic person’s right to be themselves.
- Establish a national Post-Diagnostic Service to support and assist Autistic people and parents following the assessment process.
- Put in place a public pathway of support for adults seeking an Autism diagnosis and follow-on support.
- Provide Autistic people and families with access to key workers whilst navigating the assessment and support services.
- Sanction an Independent review to both ascertain the barriers Autistic people face in accessing mental health services and appropriate services and supports, and come up with measures to address these barriers.

Supporting Autistic People and Families in the Community

- Establishment of a community fund to allow for the creation and further development of grassroots and Autistic-led initiatives
- Provide financial supports for Autistic young people and adults to access self-advocacy training and to develop supports to exercise their rights in the community.
- A national campaign to promote the roll-out of sensory friendly spaces
- Review of national guidelines on Universal Design to ensure all public buildings and spaces are accessible for Autistic people.
- Support for the roll-out of the CARA Centre for Inclusive Sport's Training for Coaches on Understanding Autism.
- Development of national guidelines and associated training on appropriate language and representation of Autistic people in media and culture
- Targeted initiatives to address loneliness, social isolation and tackle stigma amongst Autistic children and adults
- The promotion of Autistic culture in everyday Irish life through targeted initiatives by the national cultural institutions
- Formal recognition of programmes and awards which recognise and promote excellence in Autism accessibility.
- Support and recognition for the roll-out of the AsIAm Autism-Friendly Towns Programme across Ireland.

- Recognition by government of relevant ID cards and self-advocacy supports which enable Autistic people to access support in community settings.
- Identify specific pathways of support to reach underrepresented minorities within the Autism community including members of Traveller, Ethnic minorities and LGBTQIA+ Communities.
- Allocation of funding for research aligned to the priorities of the Autism community
- Provide financial supports for Autistic young people and adults to access self-advocacy training and to develop supports to exercise their rights in the community.

Providing an Adequate Minimum Standard of Living for Autistic People and Families

- Introduce a Cost of Disability Payment as outlined in the Indecon Cost of Disability Report, and ensure that Autistic people and families, regardless of employment status or support needs, has access to this payment.
- Supports provided by the Department of Social Protection should reflect the full diversity of living experience of Autistic people.
- Targeted actions to address the link between Autism and poverty, including the provision of a Cost of Disability payment and staged increases to the Disability Allowance
- Greater supports to carers of Autistic children, which include greater access to support payments, and increased rates of payment such as the Domiciliary Care Allowance and Carer's Allowance.
- Adopt a more holistic and neuro-affirmative approach to disability assessment and providing support, in line with the Social Model of Disability and the UNCRPD (United Nations Convention on the Rights of Persons with Disabilities), with an emphasis on eliminating waiting times for diagnosis and appropriate follow-on supports.
- Supports provided by the Department of Social Protection should reflect the full diversity of living experience of Autistic people

Reducing Barriers to Employment

- Amalgamate the four grants which comprise the Reasonable Accommodation Fund (the Workplace Equipment Adaptation Grant, the Disability Awareness Support Scheme, the Personal Reader Grant, and the Job Interview Interpreter Grant) into one overall scheme, similar in structure to the UK's Access to Work Scheme.
- Reform of the Public Appointment Services recruitment and interview practices to enhance Autism accessibility and the development of guidelines by the Workplace Relations Commission on supporting Autistic people at work.
- Establish a cross-education and employment system, in keeping with Universal Design principles, which Autistic people can register with at any stage of their education or career if they have a proof of their disability, or if they are considering or in the process of pursuing a diagnosis.
- Engage with Enterprise Ireland, Intreo and Local Enterprise Offices across Ireland on developing supports for Autistic people who wish to establish their own business or access self-employment.
- Harnessing the Government's Remote Work Guidelines, to address unemployment and underemployment for Autistic adults, and parents, guardians, and carers with Autistic family members. Promote the use of remote working as a way of accommodating Autistic employees in the labour market.

Promoting Safety, Equality and Justice

- Promote the development of bespoke supports which meet the needs of Autistic people, particularly women and girls, who experience domestic, sexual and gender-based violence, and targeted measures which eliminate all forms of domestic, sexual and gender-based violence in Irish society.
- Support the development of targeted initiatives to promote reduction and subsequent elimination of stigma, prejudice, and discrimination within the Autism community.
- Consideration for the needs of Autistic people who arrive in Ireland seeking international protection.

Question 1: Do you have examples of innovations that could be adopted nationally through the Autism Innovation Strategy to enhance the ways in which Autistic people access services and receive support?

Access to assessments: An assessment is key in identifying the needs of an Autistic person, in empowering an individual to understand their strengths and support needs and differences. Such an assessment should determine the level of support and services that may be appropriate. Currently Ireland's approach is characterised by long waiting lists and a reliance on private assessments, which can be incredibly cost prohibitive for families. Our recent "*Every Child Count's*" Report indicated that 42% of parents or guardians have had to wait over two years to receive a formal Autism diagnosis for their child. 54% felt very dissatisfied with the overall level of support services from the HSE. 65% of respondents felt dissatisfied with broader disability services in Ireland. Currently there is no public route for Autistic adults to receive an Autism diagnosis which poses many challenges. Access to Autism assessments for adults must form a part of this Autism Innovation Strategy. This will require increased State capacity to provide timely access to assessments and supports for children and adults, such as Speech and Language Therapy, Psychology and Occupational Therapy, for Autistic people. This is line with recent High Court Judgement's on access to services and diagnosis under the Disability Act, 2005.

The following list outlines several international innovations that have streamlined the assessment process and enabled greater provision of services:

A holistic, unified human rights-based approach to the diagnostic process and service provision with a person-centred focus is needed. It is important to consider the transitions Autistic people will face throughout their lives, from childhood, adolescence, and adulthood. Just as no two Autistic people are alike, supports must be tailored to the individuals needs and circumstances, and must prioritise an Autistic person's dignity, autonomy, and ability to make their own decisions about their lives.

Moving towards more inclusive approaches rather than persisting with gendered perceptions of Autism that conflates being Autistic as impacting mostly men and boys. For example, as part of the Malta's National Autism Strategy, there is a focus on person centred supports and services across disciplines such as coordination between service providers, whether that involves State or other professional bodies, services that are offered across the lifespan. Currently in the Irish context Autistic children and Autistic adults face several systemic barriers when trying to access services such as Child Adolescent Mental Health Services (CAMHS), such barriers need to be removed.

In making this recommendation, we note the recent publication of the Psychological Society of Ireland's Professional Practice Guidelines for the Assessment, Formulation, and Diagnosis of Autism in Children and Adolescents which represent a sea change in attitude in assessment since the previous guidelines were published in 2010, towards a more-rights based and neuro-affirmative approach.

Coordinated multidisciplinary delivery of services and supports. Increased funding and improved service delivery to bolster existing health and educational supports to meet the needs of Autistic people is required. Along with an innovative approach to recruit and retain relevant professionals including targeted action to increase the number of university places for psychology, allied health profession courses and associated steps to retain graduates within the Irish healthcare system.

Dissemination of accessible and transparent information related to accessing supports and services across multiple platforms. This will ensure that members of the Autistic community can avail of existing supports and are aware of future developments in the community. Ensuring Autistic people have the necessary information in accessible format to advocate for their rights in the way they choose. An example of this approach in an international context is the 'Different Minds' website created by the Scottish Government as part of their National Autism Strategy.

Wrap around services (One Stop Shop, Scotland): The use of community-based hubs that provide a range of services as supports for Autistic people and families including assessment, peer to peer support, connecting with other Autistic people, family supports, and access to advice and information.

Coordination, **Collaboration & Flexibility:** There needs to be greater coordination and collaboration with the State and its agencies. This is vital in delivering a truly inclusive society. This Strategy presents a unique opportunity to share innovations that work based on the best evidence available and utilising experts and expertise from around the world. As evinced during the Covid-19 lockdowns which were characterised by increased levels of collaboration between the State, voluntary bodies, and charities resulting in many innovative responses during exceptionally challenging circumstances.

Inclusive Education: A key part of a child's education is making sure that they have a place an appropriate school placement in their locality; be it a place in their mainstream classroom alongside their peers, in an Autism class in a mainstream school or in a special school.

The key to an inclusive education for every student goes beyond just physically being in the same building or from the tokenistic perception that just being placed in a mainstream classroom means an Autistic pupil is included automatically. True inclusion also involves accessing an environment and curriculum that is adaptable, flexible, and fully accessible to meet the needs of Autistic children which also meets their accessibility and support needs. Curriculums should be designed with the principles of Universal Design for Learning in mind to be available, intuitive, flexible, and accessible to every student regardless of support need or capacity. This can be achieved through several measures:

- expansion of supports,
- a substantial reduction in pupil: teacher ratios,
- recognition of the intrinsic role that Special Needs Assistants, support teachers and therapists play in a child's education,
- a cultural and attitudinal shift within key education stakeholders to support inclusive education for every pupil,
- and for provision of reasonable accommodations for every student who needs support at school.

This is so that we can get to the stage that every child can be educated in their local school in a mainstream classroom along with their peers, in the community. Until we get to this stage, this will also mean continuing to sanction and support alternative provision such as special classes, schools, and non-school based education offerings for as long as they are required. For these reasons, AsIAm argues that a “twin-track” approach which means ensuring that every child’s right to an education is met through mainstream classes, Autism classes and special schools in the here and now, whilst also gradually planning for a future where a holistic and fully inclusive education can support all students in their local school, is the best approach for establishing an inclusive education in Ireland. Our vision for an inclusive education system will also include an inclusive and accessible curriculum designed in line with the Universal Design for Learning principles, with accommodations and access to in-person supports, such as SNAs (Special Needs Assistants) (or their equivalent within a fully inclusive system), Speech and Language Therapists and Occupational Therapists. This is necessary so that every child’s right to an appropriate and inclusive education can be realised in their local school, as part of their community, and has their support needs met.

AsIAm also believes that every teacher should be able to teach all students, and teaching practices to be grounded in the Universal Design for Learning practices and principles. In line with the UNCRPD (Convention on the Rights of Persons with Disabilities) there needs to be increased training for teachers in mainstream settings. We have a comprehensive rights-based framework and the CRPD and General Comment 4 gives us a long-term roadmap to implement an inclusive education system. This cannot happen without the political will to implement a twin track approach which both urgently addresses school place shortages, suspensions, and expulsions; but also sets a vision for a progressive, holistic, inclusive education over the longer term.

Co-produced and evidence-based policy development: Engaging with relevant stakeholders including Autistic individuals, families to ensure their voice is evident within policy and legislation. Collaboration with interest groups, government departments, service providers, educators, and Autistic people themselves, who have expertise by virtue of their living experience, to get robust data related to issues that impact this cohort and inform policy.

Oversight (Monitoring) and Regulation: Making sure that the progress of the Innovation Strategy is reviewed and updated at regular intervals. While ensuring there are mechanisms to oversee and regulate disability service providers ensure that the sector is rooted in safe, purpose-driven, person-centred, and rights-based approaches which are compliant with the UNCRPD.

Transition planning: A recognition that Autistic peoples' needs will change over the course of their lives whether that relates to transitioning from primary into secondary education to employment. Planning these transitions should start as the child enters one cycle not at the end.

Employment & Social Protection supports: There is international evidence that suggests 80% of Autistic people are unemployed or underemployed. This is echoed in the context of Ireland as research conducted by AsIAm, highlighted in the Autism in the Workplace Report, indicated that 77% of respondents believed that there were barriers to getting the job they would want or starting a business. Additionally, other concerns raised related to the lack of understanding of Autism in the workplace resulting in an understandable reluctance among many Autistic people to disclose a diagnosis - only 20% of respondents requested reasonable accommodation when applying for a job. Therefore, it is critical that there is greater understanding, acceptance among employers, public bodies, trade unions and representative bodies about Autistic people, both as a cohort within the disabled community who face particular barriers to accessing the workforce, and whose skills, talents and personal qualities can make a substantial contribution to Irish society. This is explored in more detail, along with recommendations for supporting Autistic people to fully access the labour market, in our Submission to the Department of Social Protection on the Reasonable Accommodations Fund, and in our Same Chance Toolkit for employers.

Question 2: Do you have examples of good practice in terms of the empowerment of people with autism that could be adopted nationally through the Autism Innovation Strategy?

There are several examples of good practice that the Autism Innovation Strategy can use to empower Autistic people. Article 4(3) of the United Nations Convention on the Rights of Persons with Disabilities states that:

"In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations."

This really strikes at the core mantra of the disability rights movement - "Nothing about us, without us" - which should permeate all actions through the Strategy and Autistic people, as advocates or through their representative organisations. Too often, the Irish State views Autistic people through a charitable lens, and not as having rights, dignity, agency, or independence over their lives. The State's attitude towards Autistic people is rooted in the Medical Model of Disability, who are often seen as recipients of care and where services and supports are often offered on a grace-and-favour, charitable basis. This medicalised approach which often has the effect of pathologising Autistic people can be seen both across many of the State's services and supports. This often means that the interests of the State and service providers often takes precedence over vindicating the rights of Autistic people and families. This is at odds with the principles and the spirit of the UN Convention on the Rights of Persons with Disabilities and highlights the need for Autistic people to not just have a seat at the table, but also be proactively involved in developing and co-producing policies, practices and supports which support Autistic people across the life course.

Another example of good practice would be to involve Autistic people at all stages of the development and monitoring process. This would help to ensure that the Autistic voice and experience is centred throughout all stages of the Strategy's development and implementation, alongside the critical perspectives of families. An example of such a body internationally is the Autism Advisory Council, which is chaired by an Autistic lawyer, Dr Alistair de Gaetano, and which is comprised of

Autistic adults. The Council also contains members from across a range of stakeholders, such as families and professionals, and is tasked with engaging with the community and with overseeing how the Strategy is implemented to advance the rights of Maltese Autistic people and families.

Question 3: Do you have examples of good practice in terms of awareness raising that could be adopted nationally through the Autism Innovation Strategy?

The following section outlines some examples and recommendations of best practice in line with the UNCRPD (United Nations Convention on the Rights of Persons with Disabilities) which should be considered.

1. **Tackling misconceptions, stigma, and discrimination (as seen in UK, Scotland, Northern Ireland, and Malta)**: Raising awareness through national campaigns through mainstream media, social media, and print, can be a particularly important way of raising public awareness about Autism. Central to this campaign should be the voices and experiences of Autistic people and families. Engaging with members of the Autistic community and families are a key factor to understanding the lived experience, so campaigns should include the Autistic voice and reflect both the strengths and the needs of the Autistic community. Such a campaign should take a rights-based approach to understanding Autism which recognises and celebrates the diversity of the community, which affirms the right of Autistic people to proudly be their Autistic selves in society.

2. **Increased social inclusion of Autistic people**: This is integral in reducing structural and systemic barriers that many Autistic people face. Our recent "Attitudes to Autism Poll" by Core Research, which was included in our Same Chance Report, explored the public's attitudes towards Autism.

   In this poll, we found out that over half of respondents believed that Autistic people were treated more negatively in society, particularly among those who know an Autistic person. 8 in 10 respondents also said that knowing an Autistic person influences how they behave around an Autistic person. Respondents felt that they would be more likely to associate being Autistic with positive descriptors like "loyalty", "honesty", "trusting" or "attention to detail" if they personally knew an Autistic person. However, many people are likely to associate being Autistic with having difficulty making friends, not making eye contact, anxiety, or a lack of empathy.

These findings help to build a more complete picture as to how pervasive the barriers that Autistic people face in Irish society. Greater accessibility will have a knock-on effect of increasing awareness as acceptance. This can be achieved through increased universal design across all areas of Irish society. For example, in 2018 DCU (Dublin City University) was designated, following a lengthy research process led by our organisation, as the world's first Autism-Friendly University which was characterised by increased supports, accessibility, and visibility across campus to empower and encourage the students. This includes *inter alia* 'quiet spaces', 'sensory sanctuaries', 'training', 'the establishment of neurodivergent societies at universities' and 'increased recognition of neurodiversity across society."

3. **Joined up information and advice:** Within public buildings and public transportation systems, improved signage, wayfinding tools and accessible online Government platforms would assist Autistic people in navigating the often-cumbersome makeup of public services. Many of our community members when engaging with public services very often comment on the lack of coordination and difficulties in accessing basic information and results.
4. **Creating accessible environments:** A key part of building a more inclusive society for Autistic people is by ensuring that public spaces are accessible to Autistic people, in line with Disability Act 2005. Whilst this will look different depending on the type of space, this can include incorporating sensory rooms or sensory gardens, reducing environmental stimuli such as bright lights, loud noises, or strong smells, developing visual guides, or making Government websites more accessible.

5. **Representation of Autistic people**: If you cannot see it, you cannot be it. When considering the development of Autism specific policy or legislation there is a need to have representation from within the Autistic community, particularly in the decision-making process. This was a key feature of

President Biden's address on World Autism Awareness Day 2021. It is critical to ensure that the diversity of the Autism community is reflected in consultations and participation, including Autistic women and girls, Autistic members of the LGBTQIAP+ community, Autistic people with co-occurring differences or disabilities, Autistic members of the Traveller community and Autistic people of other marginalised groups.

6. **Effective monitoring and reviewing process** Several countries that have adopted an Autism Strategy have explicitly set out the need for monitoring process and progress. This is important to ensure that any methods used are effective in addressing needs on the ground. Whilst also setting out a vision for building a more equal society for Autistic people and families. For example, in Malta, the task of monitoring how their Autism Strategy would be implemented was given to the previously mentioned Autism Advisory Council, which involved a range of stakeholders, including Autistic people and families, professionals and civil society. Additionally, the Scottish Government recently published an independent review of the implementation of their 10-year Autism Strategy, which provides key learnings and insights for Ireland in terms of barriers to implementation, appropriate resourcing, and targeted goal setting.

7. **A rights-based, neuro-affirmative approach towards disability assessment:** The European Disability Forum in its recent Position Paper, *Social Protection and the Welfare State*, sets out how Ireland can adopt more progressive and rights-based approach to disability assessment. Some examples include ensuring that Autistic people, Disabled people, Disabled Persons Organisations (DPOs) and disability-centred organisations are consulted and involved in the co-producing of any proposed reforms to disability assessments and the Social Protection system more generally.

   Government Departments should accept a wider range of options related to evidence of disability for applications for support, in recognising that not every Autistic person has equal access to services or supports, and that many Autistic people are undiagnosed or self-identify as Autistic. They should also ensure Autistic people at all stages of their life journey can access the support they need. This should include but not be limited to Doctor's letters, Psychologist's reports or summaries of reports, or any information which shows that a person is Autistic or is pursuing or considering pursuing a diagnosis in future. Furthermore, the application process should take a person-centred, rights-based approach and should centre on the person's dignity, capacity and agency at all stages. It should also be designed with the principles of Universal Design, with information and forms being available in the full diversity of accessible formats, and multiple ways to engage with the process.

Question 4: What are the main issues, challenges and barriers that the Autism Innovation Strategy should focus on responding to in a 12–18-month time period?

This Autism Innovation Strategy is an opportunity for Irish Society to send a strong message of inclusion and support to Autistic people and families. With that in mind it would be remiss of us not to reference in further detail the barriers Autistic people experience in Irish society. The below is an outline of some of these barriers:

Addressing barriers within the education system, including access to fully inclusive school places should be a priority for this Strategy. Accessing an appropriate school place is a perennial weekly issue for AsIAm's Community Support Team. The use of reduced timetables, suspensions and expulsions, and the use of techniques such as seclusion and unregulated restrictive practices, which disproportionately affect Autistic pupils and impact their experiences with their education should be probed and examined.

Addressing the gaps to obtaining a diagnosis and to accessing services and supports, including Speech and Language Therapy, Occupational Therapy, and Psychology. The Strategy should also address the barriers to securing a diagnosis for Autistic adults, particularly for Autistic women and girls and Autistic people from other marginalised communities and ensure that an option within the public healthcare system is available and accessible to these communities. In accessing a diagnosis there is a considerable cost to do this, the Strategy is an opportunity to look at and address the substantial financial costs many Autistic people and families experience in securing a diagnosis and after-care supports.

Addressing poverty and social exclusion: Tackling the disproportionately high levels of poverty and social exclusion which many Autistic people face living in Irish society is a critical step towards building a just society which includes every citizen. The cost of disability has been recently identified as having a considerable cost on families, with the additional costs of living with a disability being between €10,000 and as much as €28,000 for Autistic people and families. This reflects a wide variety of factors, ranging from the extra costs of meeting medical or sensory requirements, extra light and heating, accessing food, replacing lost items, opportunity costs and lost income due to caring responsibilities, accessing transport, right through to the costs of securing therapies and supports privately. This shows that the financial supports the State provides is not sufficient to cover the costs for many Autistic people and families, as well as other cohorts within the disability community, and in some cases this extra cost, and the means test system, has the effect of pushing people and families into poverty or financial insecurity. This is covered in greater detail in the section on "Poverty Traps”.

Move towards a holistic, rights-based, neuro-affirmative approach: Taking this approach should encourage a more positive direction in shaping public attitudes towards Autism, and in supporting Autistic people and families. This is reflected in our recent “Attitudes to Autism Poll” by Core Research. This poll surveyed a representative sample of 1000 adults, which explored what they knew about Autism. In this survey, we found that only 4 out of 10 adults in Ireland surveyed felt that they had a good understanding of Autism. We also held a poll within the Autism community, which was recorded in our ‘Same Chance Report’, where we asked AsIAm Cardholders members whether they believed the wider public understands enough about Autism and whether they feel supported in the community. When asked about wider public attitudes towards Autism and Autistic people, a considerable number of Cardholders, almost 9 in 10, believed Irish society did not understand enough about Autism. This demonstrates the differences in understanding between Autistic people, families and the wider public. This includes both departing from the adversarial approach the State takes towards the allocation of services and supports to Autistic people and families. An example of this is the number of recent High Court judgements around access to services.

Addressing the barriers to employment that many Autistic people (and families) experience: EUROSTAT statistics showed that just 32% of people with disabilities were in employment, when compared to the EU (European Union) average (50%). Autistic people are particularly underserved from the labour market - 85% of Autistic people are unemployed or underemployed. These barriers to employment were explored in our ‘Autism in the Workplace' Report, which we published in 2020 in conjunction with the recruitment platform IrishJobs. In this Report, we surveyed Autistic people on their experiences at work or looking for work. This survey also examined employers on their perceptions around the recruitment and retention of Autistic people.

It was evident from this data that even when Autistic people do find work, there is still significant stigma around differences and disabilities like Autism, which can negatively shape an Autistic person's experience at work and pose barriers to being supported at work. We found that 72% of people felt that they have to 'mask' or hide Autistic parts of themselves to fit in at work, out of fear that fully being themselves would have negative consequences for them at work. We also reported that less than 10% of respondents felt confident enough in their colleague's knowledge of Autism to disclose or otherwise be open about being Autistic. In this report, we also highlighted that just 20% of Autistic people requested a Reasonable Accommodation from an employer and 42% of Autistic people believed that requesting Reasonable Accommodation would hinder their prospects of finding their preferred role.

In our engagement with the autistic community, many Autistic people highlight issues around the interview processes and testing methods as barriers to finding work.

Tackle discrimination experienced by Autistic people and families: In our Same Chance Report, we highlighted that Autistic people and families are more likely to experience discrimination in their daily lives. Over 50% of those who responded to our survey believed that they experienced discrimination because they or their loved one is Autistic. The reasons for this are multi-faceted, but in general terms, many Autistic people and families cite differences in communication and sensory processing, judgement, attitude, and a lack of supports as barriers to participation. But the consequence of this exclusion goes further as many Autistic people are also more likely to experience violence or discrimination as a result.

A survey from the UK charity Dimensions showed that 73% of Autistic people, as well as people with learning or intellectual disabilities, are likely to experience disablist hate crime or 'mate crime' at some point in their lives, but less than 50% of incidents are reported to police. This augurs the need for Autistic people to be included along with other cohorts within the disability community in the process of modernising our anti-discrimination laws, including upcoming hate crime legislation. We also know that Autistic women and girls are between two and three times more likely to experience domestic and gender-based violence compared with non-Autistic women (Cazalis, Reyes, Leduc and Gourion, 2022, p136). Given the already high rates of domestic, sexual and gender-based violence in Irish society, this speaks to the need for Autistic women and girls to be proactively included in addressing these issues.

Reduce 'poverty traps' that Autistic people and families experience within the social protection system: There are several significant issues within the social protection system which impact many Autistic people, and which cause many in our community to live in poverty.

The Disability Federation of Ireland note that over 150,000 Disabled people, including Autistic people, are living in consistent poverty. Social protection increases have not kept up with either inflation or the additional costs of living with a disability, nor do they reflect the additional costs that Autistic people and families face. Whilst social protection payments are designed to provide a minimum standard of living to keep people out of poverty, it does not address the inequalities in society which can trap people into poverty. When the Government in 2020 introduced the Pandemic Unemployment Payment (PUP) of €350 per week, to protect the incomes of workers who had their work disrupted due to lockdowns, this brought the experiences of poverty and hardship felt by Autistic people and families into sharp focus.

Many Autistic people and families, as with other cohorts within the disability community, often rely on social protection from the State as a key source of income. Adding to this financial pressure is that many families often have a least one parent who must curtail their working careers by reducing their work hours. Many of these individuals take career breaks or leave their roles to look after and advocate for their children, often saving the State money in the process but at great financial cost to families.

The Department of Social Protection's approach to assessing disability is very medicalised, basing their findings solely on a person's perceived functional capacity. This contravenes Article 28 of the United Nations on the Rights of Persons with Disabilities and leaves many people who do not have the means to secure a diagnosis, or do not fit into narrow conceptions of disability or difference shaped by clinical professionals, with no supports. These conceptions may often pathologise Autistic people, portray Autism as a 'disorder' needing to be 'cured' or 'treated' or seeing a person's accessibility requirements as 'deficits. This often bears little reality to many Autistic people's experiences living in society, and leaves those who do not reach a 'functioning' threshold, to have to manage by themselves at work. As with many cohorts within the disability community, many Autistic people find the expectation to have to constantly prove the extent of their difference or disability to be intrusive and humiliating, often causing considerable anxiety and distress. The lack of dignity in this process is out of step with a rights-based, holistic, and person-centred approach under the UNCRPD.

In our submission to the Department of Social Protection, we argue for Ireland to take such an approach to assessing needs and for supports to reflect the full range of diversity and lived experiences of Autistic people and families, rather than relying on a punitive means test approach.

Access to justice is a significant issue for many Autistic people and families for a variety of reasons, not least as a consequence of being a marginalised group in Irish society. Many people in the community access the legal system the same ways as neurotypical people do to vindicate their rights, such as to an education or to essential services, or they might come into contact with the criminal justice system. This can be complicated further if it intersects with gender identity or expression, ethnicity, sexual orientation, socio-economic background, other disabilities, or forms of neurodiversity or if they are a member of the Roma/Traveller Community. However, many Autistic people and families we engage with have negative experiences with the legal system, which can impact their faith in the justice system. We also note the impact that media coverage can have on wider public attitudes to Autism, and that sensationalised coverage or reports which include misconceptions about Autistic people and the propensity to engage in criminal activity, can cause great harm to the community. AsIAm explored these issues in greater detail in our Submission on Courts and Courthouses, where we recommend the following actions:

1. Mainstream Autism and neurodiversity into the Courts Service's future plans on physical and virtual accessibility.
2. Increase resources to ensure that Autistic people have full access to court buildings in accordance with Universal Design principles, to meet the Autism community's diversity of needs. Such measures should include access to quiet spaces, providing separate waiting areas for witnesses and defendants, accessible signage, flexible court schedules, reducing sensory stimuli and other

measures. Mainstream these access considerations into all future builds and renovations.

3. Ensure that all information related to Court Service's activities is fully accessible to the Autistic community, including Easy-to-Read.
4. Ensure that all courts put pre-trial preparation/support in place for Autistic people, including courtroom visits in advance of the hearing, and information on what to expect at court.
5. Provide measures for courts to facilitate advocates or 'appropriate adults', to support Autistic people throughout the court process.
6. Ensure that courts have the option of making hearings less formal and intimidating for Autistic people, including the removal of gowns/wigs, the use of pre-recorded evidence or the use of Plain English, where appropriate.
7. Coordinate with relevant stakeholders to ensure that court staff receive timely information about an Autistic person's access needs, including other disabilities or mental health conditions before proceedings.
8. All Court Service staff, legal professionals, Gardaí and prison staff should receive the appropriate information, including Autism Acceptance and Understanding Training and Disability Equality training on how to engage with Autistic people, and people with other differences or disabilities, based on best practices and delivered by Autistic-led and disability-centred organisations.

Question 5: Do you have suggestions for clear and impactful actions that could be included to ensure that the Autism Innovation Strategy responds clearly and directly to the main issues, challenges, and barriers that you have identified?

As Ireland's National Autism Charity, AsIAm has several actions that can be taken to ensure that that the Autism Innovation Strategy responds to the needs of Autistic people and families in Ireland. All supports and services should at its core be person-centred, holistic, and rights-based, be compliant with Ireland's obligations under the United Nations Convention on the Rights of Persons with Disabilities and should fully respect the person's capacity, independence, and agency. It should also reflect the breadth of diversity of living experiences of both Autistic people and families living in Irish society, as well as the experiences of and people with disabilities and neurodivergent people where appropriate. We also recommend that the Department should also include the following actions under the Strategy:

1. **Meaningful progress:** A clear plan towards achieving meaningful progress in addressing the gaps in accessing school places, securing a diagnosis, services and supports. Many in the community identify this as a key issue which should urgently be addressed, and the Government should take steps to ensure that waiting lists for accessing services, such as Early Intervention services and post-diagnosis supports are addressed with a sense of alacrity.

2. **Diagnostic pathways:** A key action would be to establish a diagnostic pathway within the public healthcare system for adults who wish to pursue a formal Autism diagnosis in a timely manner. For many Autistic people, often the costs that come with pursuing a diagnosis, and with securing supports afterwards such as reasonable accommodations in work or in education, can be a barrier to getting any supports needed. These issues will need to be addressed through this Strategy.

   Other barriers which were highlighted is a lack of access to in-person supports such as Support Workers or Personal Assistants, as well as an overly restrictive 'functional capacity' assessment which can make accessing supports out of reach for many Autistic people. The expectation of having to keep proving the impact of a person's difference from a lens of having a 'deficit' or 'disorder' often causes considerable trauma, distress, and anxiety for many Autistic people, particularly if it adds to the stress or anxiety living in a society which is built with neurotypical people in mind.

Many families also fear how the process of obtaining a diagnosis for their child will go, if the clinician perceives the child's characteristics as 'deficits', and that deviating from viewing their child's needs in a negative light will mean losing access to vital supports they have. Often because of the barriers to accessing timely services and supports across the healthcare system, there are many Autistic people who self-identify as Autistic, but may be either waiting for a diagnosis, or considering pursuing a diagnosis but may not have the means or the opportunity to do so. AsIAm believes that accessing supports should not necessarily be contingent on receiving an official diagnosis and that every Autistic person should be entitled to access support where required.

3. **Address present needs, plan for the future:** Another key action which AsIAm identifies is that, in the medium term, that a transition towards a fully inclusive education system will need to take place to ensure that every child could be educated in their local school, both comply with the Article 24 of the UN Convention on the Rights of Persons with Disabilities and with General Comment 4. AsIAm argues that a "twin-track" approach towards inclusive education needs to take place, which ensures that every child's right to an education is vindicated through having access to an appropriate school place in the here and now, including Autism classes and special schools, but also engaging in systemic and structural reforms which support every child's right to be educated and be included in a mainstream classroom with their peers in their local school.

4. **Tackle poverty and social exclusion:** Autistic people experience disproportionate levels of poverty and social exclusion due to a myriad of factors. Introducing a Cost of Disability Payment which addresses some of the economic and social costs of being Autistic, and significant increases to the payments such as the Disability Allowance and Carers Allowance, can go

some way towards addressing the hardship that many Autistic people and families' experiences, particularly those most at risk of poverty and social exclusion.

5. **Neuro-affirmative approach:** Adopt a more holistic and neuro-affirmative approach to disability assessments and providing support, in line with the Social Model of Disability and the UNCRPD (United Nations Convention on the Rights of Persons with Disabilities). The Irish State usually adopts approaches which are rooted in the Medical Model of Disability or delegates the provision of disability services and supports to charities, or which takes a deficit-based or behaviourist approach towards the support needs of Autistic people. This includes the prevalence of Applied Behavioural Analysis and Positive Behavioural Support, which many Autistic people cite as a chief cause of distress, anxiety, and trauma. These practices are deeply harmful for our community and are out of step with a rights-based approach to supporting Autistic people set out by the UN Convention on the Rights of Persons with Disabilities.

   The Autism Innovation Strategy offers an opportunity to depart from the charitable approach the State has taken towards supporting Autistic people and families. A move towards a rights-based and person-centred approach which supports the Autistic person’s will and preferences, and the right to be their Autistic selves is needed. The State should also move away from approaches which pathologise and aim to ‘fix’ or ‘cure’ Autistic people to fit into neurotypical norms. Such assessments should take a comprehensive approach by examining a combination of a person’s difference or disability, their lived experience, support needs or requirements and wider societal and attitudinal barriers. It should also provide opportunities for Autistic people, or peer advocates or representative organisations, to provide input into the process if the person chooses to do so.

6. **Address the employment gap:** AsIAm notes that unemployment and underemployment is all-too-often the reality for Autistic people and families in Ireland. This is despite many in the community expressing a desire to find work. AsIAm believes that the Autism Innovation Strategy is an opportunity for the Government to provide greater support to Autistic people who wish

to find employment in their chosen field, and to address practices which inadvertently or by design disadvantage Autistic jobseekers.

AsIAm has highlighted these barriers to employment in the ‘Autism in the Workplace’ Report and in the ‘Same Chance Toolkit’, both developed in conjunction with IrishJobs, and in our recent submission to the Department of Social Protection on the Reasonable Accommodation Fund.

7. **Tackle discrimination**: Prevailing attitudes towards disability, Neurodiversity, and to neurodevelopmental differences or disabilities like Autism, both within organisations and across society, can also influence whether an Autistic person might feel comfortable or safe to be open about being Autistic in society. In our most recent reports, AsIAm highlighted that Autistic people and families are more likely to experience discrimination than their non-Autistic peers, which can be compounded if they also come from other marginalised communities, or if they have other differences or disabilities. This can be shaped by wider public attitudes towards Autistic people, which can be based on misconceptions or stereotypes, and their prevalence can make it harder for many Autistic people to be open about being themselves in society.

   This stigma, that follows these attitudes can lead Autistic people to feel that they need to ‘mask’ or hide parts of themselves that others might feel uncomfortable with to fit into society. As the COVID-19 pandemic shows, ableism, or prejudice and discrimination against people with disabilities, is prevalent within Irish society, and stigma and prejudice within society can be more likely to be exposed to violence, exploitation, discrimination, and abuse, and to disablist hate crime or ‘mate crime’. It equally speaks to a ‘double empathy’ problem in terms of understanding and acceptance between Autistic and neurotypical people. All these measures speak for the need for Autistic people to be included alongside other cohorts within the disability community in any anti-discrimination measures taken by the Government, including in upcoming hate crime legislation, and for Irish society, including the Government, to take a holistic approach towards accepting and including Autistic people.

8. **Address the ‘poverty trap’ many Autistic people and families experience:** We know that many Autistic people and families are at greater risk of poverty and social exclusion than non-Autistic or neurotypical people, and that there are significant costs associated with being Autistic or with raising a child who is Autistic or who has one or more other differences or disabilities. These costs have been set out in extensive detail both in the Department of Social Protection’s Cost of Disability Report and in research conducted by Dr Aine Roddy. Extend periods in which Autistic people can retain any supports they use within the Social Protection system, such as the Medical Card, Free Travel, when they are in employment to prevent any sudden loss to entitlements if their employment status changes, would be a positive step in tackling some of the factors that contribute Autistic individuals and families falling into poverty traps.

9. **Awareness campaigns:** Develop awareness campaigns which highlight and promote a rights-based and neuro-affirmative approach to Autism and other differences and disabilities in line with the Social Model of Disability. Also include and involve Autistic people in other awareness campaigns promoted by the Government.

Question 6: What specific or bespoke challenges or barriers do people with autism in Ireland face and how can existing policy responses be strengthened?

Many of these challenges and barriers have been alluded to already throughout this document.

- Harmful narrative: Discrimination/stigma and social exclusion
- Access to services
- Access to supports
- Access to an appropriate education
- Autistic women/girls (lack of diagnosis & anorexia, communication with health services)
- Employment (see previous sections)

Autistic people want many of the same things in life as their neurotypical peers - including to be accepted and appreciated for who they are. People within the Autistic community aspire to live in a country where they do not have to advocate for themselves to simply have the same opportunities as everyone else. Autistic people merely want the Same Chance.

Autism as we know can be experienced in a range of diverse ways specific to the individual, many people experience differences related to communication or sensory processing, many within the community will experience barriers throughout their lives. This can be attributed to a lack of understanding among public attitudes towards Autistic people which can perpetuate negative stigma, characterising the Autistic identity as being one of 'deficit' rather than difference. How we perceive an issue can determine how we address it. There is a need to change the narrative around Autism, moving towards a neuro-affirmative approach, involving the appreciation of difference, whilst also recognising the disabling aspects of living in a society which often favours neurotypical people.

Access to assessment & services

One of the main barriers identified by the Autistic community is the lack of access to the assessment process and services.

This is a fundamental challenge currently for Autistic people and families, and the wider disability community. There are over 40,000 children in Ireland waiting on an Autism assessment or essential support such as occupational therapy, speech and language and psychological services (*Dáil Éireann* debate - Tuesday, 8 Mar 2022). Other issues highlighted in our recent data includes the lack of connectivity of services and financial barriers associated with accessing supports in the private sector. While there is no 'one size fits all' approach to the provision of services for the Autistic person, research indicates the importance of early interventions in the development of Autistic children, and that timely access to supports are critical in this regard.

Access to education

Access to an appropriate education is a fundamental right for all children in society and has been addressed previously in this submission. The importance of this cannot be understated or dismissed and every effort must be made to vindicate this right. For Autistic children accessing this right can be a source of distress, as they try to ascertain an appropriate school place for their Autistic child whether that be in mainstream, Autism class or special school. Such challenges are fraught with uncertainty, social isolation, and the lack of consistency.

According to our recent *Appropriate School Place Survey* 2022, it is estimated that there are currently 267 children that do not have an appropriate school place with 112 children waiting between 1-6 years for a school place. In line with the UNCRPD there is a demand for mainstream education as evidenced in 56% of children that had psychologist reports recommending an Autism class within a mainstream school. However, many Autistic children in mainstream settings are not receiving adequate support as evidenced by less than 77% of respondents reporting that their child was not receiving adequate support in their current learning environment, and 57% of children in school surveyed are on a reduced timetable.

Autism in women and girls

There is an under recognition of Autism in women and girls compared to men and boys. Recent research in Northern Ireland (Department of Health review) has suggested that almost four times the number of boys diagnosed compared to girls The lack of diagnosis is often attributed to the 'female identity' (Bargiela, Steward and Mandy, 2016, p 3281). Putting it simply, women and girls are often socialised differently to boys with an emphasis on compliance. There is evidence to suggest that a considerable number of women receive a diagnosis well into adulthood.

Many Autistic women compensate by 'masking' so called as to assimilate into a more neurotypical identity to avoid rejection or out of fear of judgement (Hull, Petrides and Mandy, 2020, p311). While this is a common coping mechanism, it is counterintuitive and can negatively impacts Autistic woman's mental wellbeing.

Autistic women are subject to additional inherent risks. These can range from their social experience in the world, negative interactions with health services and negatively impact their sense of wellbeing. While there is a lack of Irish data related to this cohort, international research has suggested that Autistic women have a higher likelihood of various forms of abuse (autistica.org.uk 2022). Studies have shown that Autistic women and girls have a significantly higher risk of experiencing sexual violence compared to their neurotypical peers (Graham Holmes et al., 2022, p1). Autistic girls also have a higher likelihood of experiencing an eating disorder. A study in the UK indicated that 1 out of every 5 Autistic women is anorexic (autistica.org.uk 2022).

Autistic women engaging in healthcare settings may require additional supports. Evidence suggests in relation to reproductive healthcare, Autistic women may have an elevated risk of pregnancy complications (Graham Holmes et al., 2022, p2). We must endeavour to create an inclusive and diverse approaches that reflect all members of society and the intersectional ways in which Autism and disability may be experienced.

The State can help to support Autistic women in the following ways:

- Greater access to supports at all stages of the life cycle. This will allow for opportunities to access supports and accommodations. For example, within work and healthcare settings that are already part of the policy/legislative framework. Additionally, adult diagnosis has been shown to facilitate greater levels of self-acceptance and help Autistic people to seek out their 'tribe' thus relieving social isolation.

- Training clinical professionals in best practices in Autism acceptance and understanding
- Ensuring access to healthcare treatment is flexible to meet the needs of Autistic women, but particularly regarding women's health such as access to IVF treatment, gynaecologist appointments, cancer screenings, etc.

How can existing policy be strengthened? (Meaningful implementation, review & monitoring process, and evidence-based approaches to policy).

The barriers and challenges faced by Autistic people are multifaceted and complex. When considering the overarching policy approach, there needs to be an overall paradigm shift from one of the medical model approaches to one of taking a neuro affirmative & human rights approach**.** There must also be a more collaborative person-centred approach between the Autistic person, their families, service providers and educators. Additionally, there is a need for robust data to inform policy design and performance.

There is also a need to review and monitor process and progress of existing polices to enable better planning, such reviews should include:

- **Review legislation related to School Admissions Act 2018**
- **Review of the EPSEN (Education for Persons with Special Educational Needs) Act 2004**
- **Review of the Disability Act, 2005**
- **Equality legislation**

When considering the current policy landscape in Ireland there must be meaningful implementation of evidence-based policies. On paper we have a legislative framework in the form of the UNCRPD, the Disability Act and EPSEN 2004, however we consistently fail at the implementation stage of the policy process. For example, when considering education in relation to this cohort. According to UNSECO (2019), education is a fundamental human right (Doyle, Muldoon, Thompson, and Murphy, 2021). The right to education is enshrined in Art 42 of our Constitution and section 12 of the Education Act 1998 and the EPSEN Act (2004). Most recently there are provisions within Irelands commitments within the

Art 24 UNCRPD, which governs the right to an inclusive education. It should be noted despite its introduction in 2004 the EPSEN Act has never been fully implemented. Ireland continues to fall short of its obligations under the UNCRD and we have yet to ratify the Protocol.

International example of best practice: Britain

Since 2009 there has been a concerted effort to address issues that impact the Autistic community in Britain. While there is still work to be done, their approach is a learning opportunity for Ireland. Some of the actions taken were:

- Establishment of the Autism Act (2009) followed by two strategies in 2010 and 2014, resulting in a 99% increase of awareness within British society.
- Establishment of the All-Party Parliamentary Group on Autism (APPGA) cross parliamentary campaign to raise Autism awareness and improve services for Autistic people and families.
- Increased access to assessments.
- Collaboration between the NHS (UK National Health Service) and local authorities related to service delivery.

Question 7: What innovative, empowering and awareness raising actions would you suggest the Autism Innovation Strategy include to compliment, incorporate or enhance ongoing actions under the National Disability Inclusion Strategy and the Comprehensive Employment Strategy for People with Disabilities?

AsIAm sees strategies such as the Autism Innovation Strategy and future policies aimed at supporting Autistic people and families as complementary to, and not separate from, wider disability law and policy in Ireland. In turn, we also believe that Autism and other forms of neurodivergence should also be included in both policies aimed at supporting people with disabilities and mainstream policies more generally. It is important that these policies should be inclusive of the fact that Autistic people and families have a diversity of needs across the life course, that many Autistic people also have other differences or disabilities or may experience other forms of disadvantage which impact their experience in living in Irish society. Equally, AsIAm also believes that Autistic people and people with other forms of neurodivergence should not be excluded from being protected under existing laws and policies related to disability, as although many Autistic people may prefer to see being Autistic as a difference, and not just as a disability, they do face a wide range of discriminatory barriers within society which have a disabling impact when living in society.

Question 8: Recognising that language evolves and changes as our understanding of autism evolves and changes, how should existing or novel terminology be used throughout the Autism Innovation Strategy to refer to autism and people with autism?

Language can be a powerful and evocative way of describing ourselves, and using the terminology preferred by the community can be challenging for all of us. We all have preferred ways of being addressed and words can have a powerful impact on our emotional wellbeing. It is potentially more complex when speaking to people within the Autistic community. For that reason, AsIAm are including a comprehensive guide related to language and Autism as part of this document **(see Appendix B).**

There are a few things to keep in mind moving forward. It is important to focus on empowering language. For example, some people may choose identity first language such as “Autistic person/people or “Disabled people” while others may prefer person first language (“people with disabilities”). Additionally, it is important to avoid emotive language to describe the experiences of Autistic people and families, such as (“suffering from”, “is a victim of”, “Overcame their”), which ‘others’ or minimises their experience (“special needs”, “special”, “DisABILITY,” “Different needs”, referring to neurotypical people as normal) or which portrays an Autistic person as inspirational just for being Autistic (“Overcame”, “In spite of”). You can find more details in the Language Guide in the Appendix.

Appendix A Focus Group Report

AsIAm commissioned Kelleher O'Meara in February 2022 to facilitate a series of **four Focus Groups**, which consisted of **three parent groups of Autistic children and adults** and **one group of Autistic adults**, both chaired by Colette Kelleher and Kathleen O'Meara and facilitated by AsIAm staff members. Every individual within the group was asked ten questions about what they would like to see in an Autism Innovation Strategy. This commissioned consultation provides a level of insight from a person-centred perspective, which should inform the development of a Strategy designed to allow Autistic people to live as equal citizens. It is clear from the findings that a lot of Autistic people face major barriers in negotiating every stage of their life journey, from early childhood to adulthood. Their families equally face major struggles in securing the support needed for their children at every age.

The lack of awareness and understanding at every level of society is cited as one of the barriers facing Autistic people and families and which they want to see the Autism Innovation Strategy address. This lack of awareness and understanding of being Autistic can often be acute among professionals whom Autistic people and families meet-at all levels of healthcare and education, from pre-school to third level but also in public spaces such as transport and leisure facilities, as well as in places of employment.

The waiting lists for a range of essential services, which forces many families to pay for private services and care, is a considerable burden to many.

Across all services- health, education, housing, transport, disability services- and employment, Autistic people have barriers to accessing services which are suitable and appropriate or supports which match their needs or preferences. A "One size approach does not fit all" and this is evident in our engagement with Autistic people and families, all who have a diversity of strengths and support needs which are often unmet by the State. The lack of services and supports for Autistic people is brought about by a myriad of reasons, including a lack of understanding, affirmation by society and training among key professionals such as teachers, judiciary, lawyers and healthcare practitioners at every level, and the State's reliance on a charitable, grace-and-favour approach to allocating supports.

Please note below are some insights into some of the responses we received during our consultation with Autistic people and families, which encompass direct quotes from Autistic people and families.

Questions	**Response**
Q.1 What do you think are the main barriers in accessing disability services for the Autism community?	"No single point of contact when it comes to accessing services and support. Clear clack of information sharing, guidance, and direction about what services are available. It is hard to navigate an opaque system" "Excessive and lengthy waiting lists" "No proper services for Autistic people or only a few. Services not designed for individual's needs. Very poor understanding of Autistic people" "Having to access supports privately, costs and affordability and equity which favours those in a position to pay" "Services are not linked. No clear progression from different stages of development; child, teenage, adult, independent living. No data sharing. Big gap between child and adult services" "No continuous professional development for healthcare and educational professionals" "Lack of understanding of our community's requirement by civil service and policy makers"
Q2 What do you think are the main barriers to accessing healthcare for the Autism community?	"Lack of variability in levels of awareness, empathy, understanding experience and knowledge of Autism in the general healthcare system" Lack of training of HSE staff including GPs and continuous professional development"

	“Accessing quiet spaces is not understood within the healthcare and the importance of it. Sensory issues in some buildings and medical environments can be overwhelming. Accessing actual services is next to impossible, dental care in particular. Waiting to see professionals is difficult” “No Autism friendly maternity care” “A lot of passing the book, especially when it comes to mental health. CAMHS (Child and Adolescent Mental Health Service) is not fit for purpose when it comes to assisting young Autistic people” “Ireland’s digital health strategy needs to include Autistic people”

Q3 What would you like to see included in an Autism Innovation Strategy that would help to address any additional costs of living for an Autistic person or in raising a child?	“Domiciliary Allowance should not be as difficult to access as it is. The carers payment is not sufficient. Higher disability payments needed” “Less red tape. A simpler application system to access grants and help for people apply for support is needed” “Lack of childcare for Autistic children and impact on parents' ability to work. A subsidy for those families is needed. A carers allowance for non-working parents, even if another parent is working” “State to cover costs of private assessments and therapies” “Allowances need to reflect the needs of the Autistic person at different stages in tehri lives and what is needed at the time. An indexed allowance” Greater subsidies around VAT (Value Added Tax) exemptions for specialist equipment and transport” “All sensory toys to be tax deductible” “Allowance for assistive technologies” “A rental scheme to trial things like weighted blankets which can be expensive, especially if they do not work” “Subsidises mental health supports e.g., Autistic coaches, counsellors for Autistic people” “Access to appropriate early intervention supports” “Funds for carers and parents to access health care, therapy, self-care, for example, massages are available in France”

	“Recognise carers are real people, real workers that save the government millions each year”

Q4 What would you like to see included in an Autism Innovation strategy in terms of accessing education?	“More preschool classes for our children. Review of the AIM (Access &Inclusion Model) for preschool to include Special Needs Assistant and access to supports for additional needs. Currently the only option is home tuition. Big groups in ECCE (Early Childhood Care and Education) scheme do not work for Autistic toddlers” “Mandatory training for all primary and secondary school teachers in relation to understanding the condition” “A change to the qualifying mechanisms of the Junior cert, Leaving Cert and college programmes. One pathway does not fit all” Remote/online education options at university level. Full degrees should be available for fully remote students” “Reduction in bureaucracy and delays in relation to applying for Special Needs Assistant hours and resource hours through the Department of Education” “An extended school year, summer education programme needs revamping” “Educate peers to accept children with differences” “Include life skills in formal education” “Support for students who are masking in school” “Data gathering/forecasting identifying the gaps in education around accessing school places”

Q5 What would you like to see included in an Autism Innovation Strategy in terms of accessing housing?	“Assistance for Autistic people to apply for housing support. A clear application process” “Housing options for independent, community-based living with supports if needed. Communities of support built around housing to provide as much independent living as possible” “Needs based assessment and assistance in accessing social and affordable housing where being Autistic is taken into consideration” “Financial and logistical planning so that one and two bed housing is being included in plans to allow for Autistic adults to live independently, with supports needed” “An allocation of social housing for Autistic people and families” “Sensory Housing” “Research and use best practice from other countries around meeting needs in relation to housing”

Q6 What would you like to see included in an Autism Innovation Strategy in terms of accessing work	"Incentives/mandates for medium/larger companies to employ Autistic people. Government should encourage and support employers to provide jobs to Autistic people. Coaching for employers" "Employees-information/assessment of strategies by which Autistic people can identify their own strengths and weaknesses in the workplace" "National Training for employers to showcase the advantages of having a diverse workforce, the traits and strengths Autistic people bring to the workplace. General training on Autism for employers" "Grants for employers to buy sensory equipment and create sensory spaces" "A system which allows Autistic people to work and keep their benefits including access to housing, medical care and Disability Allowance" "Workplaces to review to ensure there are no barriers for Autistic people" "Employers to identify and promote specific jobs which are Autism-friendly" "More understanding and support for staff with an Autism diagnosis" "Penalties for employers who do not make reasonable accommodations for Autistic people" "Work experience opportunities for Autistic people to try different types of work in order to find something that suits" "Learn from best practice in other countries" "Flexible working which allows Autistic people to work"

	"Best practice guide in inclusive interview processes" "A neurodivergent job portal listing" "Funding for workplaces to become Autism-friendly" "Civil service jobs to increase disability quotas" "Government and Health Service Executive to employ people with an interest in Autism to work on this strategy"

Q7 What would you like to see included in an Autism Innovation Strategy in terms of accessing disability services?	“A central website” “A dedicated case worker/liaison person for Autistic people over a period of time. These workers are specifically trained to act as a contact for the Autistic person to navigate the system. A joined-up plan each individual person, based on the individual needs” “Easier access to services” “Access to ‘neuro affirmative’ therapists” “A real plan to tackle the waiting lists that would ensure access to all when the services are required, and that no Autistic person would be left on a waiting list for urgent services/supports” “Respite for parents” “A clear and understandable roadmap to navigate what is available” “A national standard so that all get the same support when required” “Better links with the mental health system”

Q8 What would you like to see included in an Autism Innovation Strategy in terms of accessing transport?	“Quite (sic) carriages on trains and Luas” “Training for transport staff, particularly customer facing staff to increase understanding about Autistic people’s needs” “Easier access to disability parking permits” “A fit for purpose school transport system. Current one is poorly managed and communicated. Department of Transports should be more accountable regarding the setting up of school transport” “Free travel passes for an Autistic person and carer where appropriate” “A waiving or reduction of Vehicle Registration Tax for semi-commercial or private vehicles currently classed as ‘people carriers or SUVs, if they are needed to facilitate day to day travel for Autistic people” “Recognition of the AsIAm ID card”
Q9 What would you like to see included in Autism Innovation Strategy in terms of accessing recreational supports?	“Incentives for Autism friendly time slots (not the times no one else wants) at sports and leisure centres including swimming pools, cinemas etc” “Training for staff who work in sports, arts, recreation, hotels and tourist attractions” “Discount for carers or free of charge to state owned recreational events” “Communication cards or boards in venues” “Autism strategy for big stadiums, museums, parks etc”

	“Requirement of all local sports partnerships to organise sporting sessions which are inclusive for all children and adults” “Funding from the Arts Council or Failte Ireland promoting art and cultural activities which promote and include Autistic people” “Accessible toilets” “To have sensory spaces at outdoor events”
Q10 How do you think an Autism Innovation Strategy should be made law, or monitored to ensure that wat is included in the strategy is acted upon by the Government?	“Having a clear structured system, with targets and milestones set and achievable dates to meet this over time. Continuous monitoring centrally of measurables and auditing to make sure on target for milestones” “Employ an Autistic led team to survey Autistic people and families about what is working and what is not” “Monitoring may need to start at ground level” “An easy online complaints/reporting system” “Creation of an Ombudsman for Autism” “Government to consult with AsIAm, self-advocates, parents and neuro-affirmative professionals” “A government led awareness campaign” “Consultation and participation by Autistic people at all levels of Government, State and Publicly funded bodies”

Appendix B: Autism and Language

As Autism has enjoyed greater visibility, understanding and acceptance in recent years, there can still be some uncertainty among wider society around what the best to say is when we are talking about Autism and about the experiences of Autistic people. In a 2016 study from the National Autistic Society, the Royal College of General Practitioners and the UCL (University College London) Institute of Education enquiring about the use of language in Autism, many Autistic adults preferred the term “Autistic person” to describe our experience of being Autistic, whereas families and professionals favoured the term “people on the Autism spectrum”.

AsIAm recognises that language can be a powerful and evocative way of describing ourselves, and that Autistic people will have many reasons for favouring one term over another. It shows that there are different ways of talking about Autism and disability, and how Autistic people might choose to identify ourselves. These are:

- **Identity-first language** (“Autistic person/people”, “Disabled people”);
- **Person-first language** (“people with disabilities”).

Many Autistic people prefer to use identity-first language, like **Autistic person (which is often capitalised i.e., Autistic person)** or **disabled person (or Disabled person)**. This is because many Autistic people see being Autistic as a core and intrinsic part of our identity, and that we embrace being Autistic as a part of who we are. We see being Autistic as either a difference, a disability, or both, that is a natural part of human diversity, and as a central part to how we experience the world. This is informed by schools of thinking like Neurodiversity and the Social Model of Disability, which both emphasise the way that society often poses disabling barriers that can impede or prevent people with disabilities, including Autistic people, from equally taking part in society.

The Social Model of Disability

The Social Model of Disability states that Disabled people are disabled by barriers within society. These barriers range from physical, communication or social barriers, to negative public attitudes, barriers accessing supports, to differences in how we socialise and understand each other. These can all make it harder for Disabled people, including Autistic people, to be fully accepted and included in society.

The Social Model supports the view that Autistic people and Disabled people have the right to fully participate in society, and that everybody in society has a part to play to address barriers which exclude or discriminate against Disabled people and Autistic people. By removing or reducing these barriers, society can support Disabled people and Autistic people to equally participate in society.

Some within the Autism community, such as families or professionals, might favour person-first language. This is because they might prefer others to see the person before our disability or difference, and do not wish to have an Autism diagnosis define who their child is or what their child wants to do. They might have valid concerns that attaching a label to somebody’s disability or difference like ‘Autistic’ or ‘disabled’ could stigmatise the person and have a negative impact on how we want to live our life.

However, there are recent movements led by Autistic self-advocates and disability rights advocates which reclaim terms that were once perceived as marginalising or stigmatising, including ‘Autistic’, ‘Disabled’, and recast these labels or identities in a more positive, empowering light. This gives the people who reclaim these terms, like Autistic people, a sense of pride, identity, and a feeling that we belong to a wider community.

You might often see many Autistic people also spell Autistic with a capital A, to recognise that we do not just see our Autism as a neurodevelopmental disability or a different neurotype, but there is also an Autistic community that we also identify and engage with, with a distinct identity and culture that we identify with and can participate in. This is distinct from the wider Autism community which can include allies like families, partners, friends, professionals (like Speech and Language Therapists, Occupational Therapists, psychologists, teachers or Special Needs Assistants) and carers and supporters. This is different to seeing an Autistic person as an individual or referring to Autism strictly as an impairment or a disability itself.

It is always important to stress that the language used about Autistic people or the Autistic community or the wider Autism community should always be guided by Autistic people, and that it continuously evolves to reflect the increasing diversity of the community. To reflect this, AsIAm uses identity-first language and "Autistic people", "the Autism community" and "the Autistic community" throughout our campaigns, our Advocacy, Policy and Community Support work, our Adult and Employment Support teams and in our Training offerings.

What is Neurodiversity?

Neurodiversity was first coined by Judy Singer in the late 1990s. It revolves around the idea that neuro-developmental differences or disabilities like Autism arise from natural differences in the human brain. The American journalist Harvey Blume, who first explored the idea in The Atlantic in 1998, noted that "Neurodiversity may be every bit as crucial for the human race as biodiversity is for life in general." (Blume, Neurodiversity, 1998).

Like biodiversity in nature, Neurodivergent people believe that there is no 'normal' type of brain, but lots of different types of brains which think and process information differently, called 'neurotypes'.

From a neurodiversity perspective, many advocates see Autism as a **'neurotype',** and as a **difference**, as well as a disability. A **neurotype** is a type of brain in terms of how a person thinks about, interacts with the world, and responds to different ways of communicating, such as body language or social cues, etc, as well as to different ways of thinking. As well as Autism, neurotypes also include other neurodevelopmental differences like ADHD, Dyslexia, Dyspraxia, Dyscalculia, Epilepsy, Tourette's Syndrome, and some mental health conditions, among other differences or disabilities.

Neurodiversity's core idea is that these neurodevelopmental differences should be recognised and respected as a natural and essential part of human diversity, and that neurodivergent people have the right to be treated as we are. We also believe that Autistic people do not always need or necessarily want treatments, cures or behavioural interventions, and that many barriers created by society's attitudes towards Autism and other neurotypes, which can disable neurodivergent people from being fully included in society.

Many Autistic people and neurodivergent people believe that society can greatly benefit by allowing people to flourish and live our lives as Autistic or neurodivergent people and being included in society without needing to 'mask' or camouflage traits other people might feel uncomfortable with. By accommodating Autistic peoples' support needs, society can help Autistic people flourish and live active, fulfilling lives in the community, and create a more inclusive society.

Neurodiversity advocates use a few terms to describe our experience of living with conditions, differences like Autism. Many people with neurodevelopmental differences or disabilities might use **'Neurodivergent'** to describe the way our thoughts and characteristics diverge or differ from what society expects of us, whereas a **'neurotypical'** person thinks and experiences the world in ways that society considers to be typical. **'Neurodiverse'** refers to a group of people who may contain one or more neurodivergent members.

No matter what language you use, the most important thing is to accept an Autistic person as we are, and to be open and willing to learn from Autistic people. Autistic people, as well as people with disabilities want to be full and equal citizens and to have our voices heard and respected, with dignity, choice, and autonomy over our lives. We do not want to be seen as objects of pity or charity, or as 'broken' individuals needing to be fixed through therapies, or medical or behavioural interventions.

Often conversations surrounding Autism, particularly people who might be perceived to have ‘high support needs’ or have a ‘severe’ or ‘profound’ disability, can focus on what is ‘wrong’ with the person or what type of care or services are needed, over what they need to live the life they want, and how they can be supported to exercise our agency and independence.

Regardless of what terms people use to identify ourselves, it is always best practice to ask an Autistic person how we would like to identify ourselves. When you are using language around Autism, it is essential to come from the perspective that Autistic people are people. We are not objects of pity, ‘broken’ people in need of fixing, or as ‘inspirational’ figures just because of our differences, as opposed to our thoughts and actions.

Fundamentally, Autistic people have the same rights as everybody else, regardless of the type and degree of supports we need, even if we might sometimes need different ways of accessing these same rights. Autistic people have the right to make decisions that affect our lives, and to receive any supports we need to help make these decisions.

If an Autistic person might be non-speaking, partially speaking or pre-verbal or prefer using different forms of communication, it is helpful to take this into account and to respect and accommodate their communication preferences. If there are family members, carers or advocates who wish to support the Autistic person, you can also ask us, and we might be able to assist you with this if an Autistic person needs more support.

What should we say?	***Why?***
autistic person/Autistic	Many Autistic people prefer “autistic person” (or Autistic person with a capital A) because we see our Autism as a core part of our identity, and as integral to who we are and how we experience and understand the world.

	Many Autistic people also see Autism as a natural part of human thinking that has always existed. Many Autistic people see our Autism as a difference and a disability, particularly if our access needs are not addressed or accommodated.
Autism is a difference and/or disability	Whilst Autism is first and foremost a different way of thinking and understanding the world, it is also considered a disability, not least in the sense that not everyone will always be willing to understand, appreciate or accommodate Autistic ways of thinking, processing, or interacting with the world. There are aspects of how society is organised and structured, like the physical and sensory environments, how we communicate, how we socialise, how we access services and supports, or society's attitudes to Autism, which can shape how an Autistic person might feel accepted and included in society. If these access barriers are not addressed, this can disable Autistic people from being accepted and included in society, and from feeling valued as an equal citizen.
Support needs	This refers to the level and the type of support that an Autistic person might need in aspects like education or everyday living, as set out by the DSM-5. This replaced functioning labels used by previous DSMs to adjudicate an Autistic person's level of support needs. These range from **Level 1 ("Requiring support"),** where an Autistic person might need some supports, **Level 2 ("Requiring substantial support")**, where an Autistic person might need more substantial or intense support, and **Level 3 ("Requiring very substantial support")**, where an Autistic person may require a lot of support or more intense supports, to go about our everyday lives.

What are some other terms that the community uses?

Allistic	This is a term that many Autistic people use to refer to a person who is not Autistic
Neurotypical	This refers to a person or people who do not have a neurodevelopmental difference or a type of Neurodiversity, such as Autism, ADHD, dyslexia, etc.

Neurodivergent people	People who have one or more types of neurodiversity or neurodevelopmental differences.
Neurodiverse	This is often used to refer to a group with one or more Neurodivergent people
Masking	This refers to when an Autistic person, consciously or unconsciously, hides the fact that they are Autistic or who hides Autistic parts of themselves to fit in with everybody else in society – such as suppressing stims, making eye contact, or having to work on how we appear in public. Masking can have extremely negative consequences for an Autistic person's wellbeing, and can often lead to Autistic burnout, so do not expect an Autistic person to not be themselves.
Autistic burnout	This is a state of intense physical, mental or emotional exhaustion that can arise because of the additional load of having to navigate a world that is not built with Autistic people in mind. This often arises from consistently masking or prolonged periods of sensory overload.
Neurotype	A type of brain in terms of how a person thinks about, interacts with the world, and responds to diverse ways of communicating, such as body language or social cues

What are some terms to avoid?

Avoid	***Why?***	***What you can use instead***

“Has”, “Suffers from” or “is a victim of” Autism or “Autism is a disease/illness” · “. . . lives with Autism.”	Clinical professionals are actively involved in diagnosing Autism and developing strategies that support Autistic people to meet our access needs, and so are often the first port-of-call when somebody is diagnosed or self-identifies as Autistic. This had often led to medicalised language being used to describe the experiences of Autistic people, which has the effect of portraying Autism in a negative light. Many Autistic people rightly have strong feelings about how Autism is referred to by professionals, which can often be at odds with how many Autistic people wish to identify as. Autism should not be considered an illness or disease. Autistic people are not broken people that need to be treated or fixed because of our Autism.	· “. . . is Autistic”
Autism Spectrum Disorder (ASD), ‘disorder’	While Autism is sometimes referred to as a ‘disorder’, often by people who may not have first-hand experience of being Autistic, a lot of Autistic people express a strong dislike to the use of the word ‘disorder’ to describe being Autistic. Many Autistic people prefer to describe being	"difference” “… is Autistic” “Autistic people”, “Autistics”

	Autistic as a "difference", rather than a "disorder". This is because an Autistic person's way of thinking is not "wrong" or "broken" - just a different way of thinking, understanding and processing the world. Autistic people do not want treatments or cures for our Autism or our Autistic traits. Instead, everyone in society can adjust to accept and include Autistic people and families.	
Autism Spectrum Disorder (ASD) Unit, Autism Unit	The word "unit" carries medicalised assumptions around how Autistic people are educated and presumes that all Autistic pupils need to be educated in segregated settings, even though this is not the case. Many Autistic people are educated in mainstream classrooms. For many Autistic people and families, the word "unit" implies that pupils who are in Autism classes are in clinical settings and that we need to be educated away from our peers, in separate classrooms or schools.	Autism Class

“High-Functioning” or “Low-Functioning” “Mild”, “Moderate”, “Severe” or “Profound”	Autism is a spectrum where no two people will experience exactly the same barriers to participation or have the same support needs. Deriving from the medical profession, these clinical descriptors were carried over into everyday use. These labels are harmful to Autistic people, and do not fully capture how Autistic people experience being Autistic or our capacity to make choices. Autism is such a diverse spectrum of ‘traits’ and differences that no two people will experience being Autistic the same way or have the same support needs.	“Support Needs”
“Asperger Syndrome”	Asperger Syndrome is no longer an official diagnosis used by clinical professionals. Asperger Syndrome refers to people who experience no speech differences, who are seen to have average or higher levels of intelligence, and who may be perceived to not need a lot of support. However, it reinforced preconceived ideas	“Autistic person”

	around Autism, which may not fully reflect what it is like to be Autistic for many people. The figure it was named after, Dr. Hans Asperger, has become a controversial figure within the Autism community in recent years. Recent studies have posthumously connected Asperger's work on Autism to a Nazi eugenics programme in his native Austria, and which was highlighted by Edith Sheffer in her recent book "Asperger's Children". However, some people also choose to identify with the term "Asperger Syndrome" (or "aspie"), as this was what we were diagnosed with at the time, or we might also identify with some of its cultural aspects. It is important that if we decide to use these terms, to respect our choice.	

Backward/Deranged/ Handicapped/R*******	Understanding of Autism and disability have evolved in recent years. For years, people have used outdated terms about Autistic people and Disabled people which reinforced harmful stereotypes around Autism and disability. Autism has inaccurately been perceived as a mental health condition or an intellectual disability, and this has led people to use derogatory terms to 'other' Autistic people. Although many Autistic people may also experience an intellectual disability or mental health condition, it is wrong to use these terms to 'other' Autistic people and Disabled people. Many Autistic people see our Autism as a part of who we are and do not wish to use terms that minimise or separate our disability or difference from our worth, dignity, experience or achievements as a person.	· "People with a learning disability"; · "People with an intellectual Disability." "Disabled people"

“Special needs”[1] (Special Needs children, Children with Special Needs) “Special”	Many Disabled people consider “special”, “special needs”, and to a lesser, to be patronising and euphemistic, as it can reinforce outdated attitudes around Autism and disability - that see Autistic people as objects of pity, rather than having rights, independence, or agency over our lives. This can be seen as euphemistic terms which can allow people who might feel uncomfortable to talk about issues relating to disability without having to directly discuss a person’s difference or disability. It is important to remember that the needs or rights of Autistic people are not “additional” or “special”. Autistic people have the same rights as everybody else, even if we might sometimes need different supports to access these rights, or to live our lives in the way we want to. “Special needs” or “additional needs” can be used in an educational or medical context to refer to pupils with additional needs	“Disabled people”, “People with Disabilities” “Autistic people” Within an education context, you can also use: “Support Needs”

	(i.e., some Autistic people, or people with disabilities who have additional needs related to our education) who might attend a special school or an Autism class for part or all the school week. Whilst "special needs”, “special education” is in use in schools to refer to the needs of Autistic children as many in the Autism and disability communities take offence to the use of this term, it is better to avoid using these terms to refer to Autism, or disability more generally.	
“Diffability”, “Handicapable”, “DisABILITY”, “Differently abled” “Overcame their Autism/disability” “Overcame the odds” “Despite/in spite of their Autism/disability” “Look past their disability” “Inspirational” “Courageous” “Defying our Autism/disability”	Whilst some people can use these terms to try to celebrate Autistic people or Disabled people, it can in fact be harmful or reinforce negative stereotypes around Autism. It can suggest that it is not OK to simply be Autistic or disabled and be part of society, that we must also be inspirational in some way to have worth and dignity in society. It also implies that our disability or Autism itself is the limiting barrier is keeping us from ever doing what we want to do, and not looking at what society can do to accept or include	“Autistic”, “Disabled people”, “People with disabilities”

"Our autism/disability did not stop us from…"	Autistic or Disabled people. Whilst an Autistic person is not inspirational just because we are Autistic or disabled, we have many positive traits that you might find inspiring. Autism and disability are not dirty words. It should not be seen as something that is taboo, a negative aspect or trait of a person to avoid, or an obstacle to overcome. It is possible to be successful, do well in life, and still be Autistic. We need not be afraid of using these terms when talking about Autistic people, as these are terms that many Autistic people prefer and want everybody to use when talking about Autism or disability.	
"Normally developing children/adults"	Using "normal" when referring to non-Autistic people implies that Autistic people are somehow 'abnormal' or 'broken' for developing differently from neurotypical people. It also infers that Autistic	"Neurotypical", "Allistic" or "non-Autistic children/adults."

	people need to be ‘fixed’ or ‘cured’ of our Autistic traits. It also fuels the idea that Autism and disability are taboo subjects to avoid, rather than something to embrace as part of the human experience. At least 1 in every 65 people are Autistic, around 1 in 10 people are neurodivergent and around 1 in 7 people have one or more disabilities, so it is highly likely that you know somebody that belongs to any or all these communities, be it a family member, a friend, a loved one, or somebody you know in the community. There have always been Autistic people – it is just that attitudes towards Autism and disability are evolving, and we know more about these differences and how to accommodate our access needs!	

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[1] Whilst the term ‘ASD’ is often used by educational and medical professionals, one may prefer to use the term ‘Autism spectrum condition’ or ‘on the Autism spectrum’ because it avoids the negative connotations of ‘disorder.’