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Department of Children, Equality, Disability, Integration and Youth

Autism Innovation Strategy

Analysis of Initial Public Consultation Submissions

April 2023

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1. Executive summary

In April 2022, Minister of State with special responsibility for Disability, Anne Rabbitte, launched a public consultation process to inform the design and development of an Autism Innovation Strategy. The aim of the Strategy is to identify unique challenges and barriers faced by Autistic and Neurodivergent people and to identify ways to address these. The Strategy will focus on specific areas that may not be addressed by broader disability policy frameworks, such as the National Disability Inclusion Strategy[1] or the Comprehensive Employment Strategy for People with Disabilities.

Fifty-one responses were submitted as part of the consultation; of these, approximately 39% were from Autistic and Neurodivergent people, 18% were from parents of Autistic and Neurodivergent people, 19% were from professionals working primarily in the education and health sectors, 5% were from disability organisations, 4% were from statutory agencies and 15% were from an unknown source (all of which were anonymously submitted online though the EUSurvey platform).[2]

The clear message that came through the submissions regarding language is the preference for the identity-first language of 'Autistic person' rather than 'a person with autism'. This preference is used in the main body of this report.

Autistic people aspire to live in a country where they do not have to advocate for themselves to simply have the same opportunities as everyone else. However, there are a range of barriers and challenges that they experience in their daily lives.

The barriers and challenges that Autistic people experience in their daily lives were expressed in terms of a lack of:

- Alternative communications and robust forms of communication for all non-verbal or minimally speaking Autistic people
- Data – not having actual numbers of Autistic people at any given life stage impacts on the planning for services required and creates barriers for Autistic people in accessing the services they need
- Appropriate education
- Employment opportunities and the impact this has on income adequacy
- Health services and supports, and
- Understanding among members of the public in their attitudes towards Autistic people, which can perpetuate negative stigma, characterising the Autistic identity as being one of 'deficit' rather than difference.

[1] The National Disability Inclusion Strategy ended in December 2022 but was still in effect when the consultation was carried out.

[2] The breakdown of responses is based on information provided in submissions and the assessment of the author of this report.

Respondents also provided a range of examples of innovation in the ways in which Autistic people accessed services and were supported, and good practice in empowerment and awareness-raising. Some of the respondents made suggestions about what they see as good practice and what they would like to have in place as opposed to examples of what is currently in place.

These suggestions spanned different services but focused on education, employment and health. They included suggestions about assistive technology, community inclusion, understanding autism, and consultation and engagement with Autistic people.

Some respondents pointed out that while these examples may well be good practice, it is important to have some sort of process to determine how effective such practices and/or innovative initiatives have been in the lives of Autistic people themselves.

Specific examples were also cited. These ranged from national guidelines to various initiatives in third-level institutions, and some were drawn from international initiatives in the United Kingdom (UK) and the United States of America (USA).

Among the key elements respondents suggested for inclusion in the Autism Innovation Strategy are the following:

- Autistic people should be involved in the development, monitoring and review of the Strategy; co-production and co-design with Autistic people should be part of the Autism Innovation Strategy and delivered both in the process (how the strategy is designed) and in the outputs (ensuring that work is delivered).
- Identity-first language should be used.
- Several of the submissions highlighted that the Autism Innovation Strategy offers an opportunity to 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 self.
- A number of issues raised by respondents had to do with existing services, such as Assessment of Need, early education and care, inclusive education, and Progressing Disability Services. Consideration will therefore have to be given to aligning the Autism Innovation Strategy with existing strategies and policies, such as the Disability Capacity Review Action Plan.
- The Autism Innovation Strategy should have a human rights framework.
- Several suggestions were made regarding ways in which society could become more autism-affirming. These included national, local, and targeted approaches. It was stressed that whatever the approach, it must involve Autistic people at all levels.

- Stigma, preconceived notions about autism, and misinformation were identified as issues that need to be addressed. In addition, there needs to be a move beyond simple awareness and towards understanding of autism.
- Meaningful and early access to Augmentative and Alternative Communication should be facilitated.
- There should be an immediate transition away from damaging behavioural interventionist therapies and towards neuro-affirmative, rights-based supports.
- Public pathways to autism diagnosis for Autistic adults should be developed.
- A neuro-affirmative framework for education and health services should be developed.
- The Strategy should recognise the importance of Universal Design.
- The Strategy should address data deficits.

The underlying expectation coming through the submissions is that the Autism Innovation Strategy would change the narrative on autism in Ireland.

2. Context

In April 2022, Minister of State with special responsibility for Disability, Anne Rabbitte, launched a public consultation process to inform the design and development of an Autism Innovation Strategy.

The aim of the Strategy is to identify unique challenges and barriers faced by Autistic and Neurodivergent people due to gaps in existing services and supports. The Strategy will aim to address these gaps by identifying simple, clear actions that can make a tangible difference to people's lives under the key themes of innovation, empowerment and awareness-raising. It will focus on areas that may not be addressed by broader disability policy frameworks on the basis of additionality and complementarity.

The vision of the Autism Innovation Strategy is to achieve the meaningful inclusion of Autistic and Neurodivergent people in society and to enable Ireland to become a more autism-friendly and neuro-affirmative country.

In line with Ireland's commitment to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), Autistic and Neurodivergent people and their families, friends, co-workers, representatives and support structures will be involved in the development of the Autism Innovation Strategy from the outset, and in the monitoring of its implementation once adopted.

3. Public consultation

A public consultation was held between April and May 2022. To facilitate this consultation, the Department of Children, Equality, Disability, Integration and Youth prepared an Autism Innovation Strategy consultation paper. This provided background information about the context for the consultation, the development process for the Autism Innovation Strategy, the next steps in the process, and how people could participate in the initial public consultation.

Easy-to-read versions of the consultation paper and a consultation answer form were also produced as part of the consultation. The consultation topics and questions included:

- Identification of the specific unique challenges and barriers faced by Autistic people and how existing policy responses can be strengthened
- Examples of current innovations that may enhance the way Autistic people can access services and receive support
- Examples of good practices that help to empower Autistic people
- Examples of good practice in terms of raising awareness and deepening society's understanding of autism that could be adopted nationally
- Suggestions for clear and impactful actions that could be included in the Autism Innovation Strategy in order to ensure that the Strategy responds clearly and directly to the main issues, challenges and barriers identified
- Suggestions for innovations that could complement or enhance ongoing actions under existing strategies, such as the National Disability Inclusion Strategy[3] and the Comprehensive Employment Strategy for People with Disabilities, and
- How language and terminology should be used throughout the Strategy.

When the consultation was launched, submissions were invited from anyone with an interest in participating in the development of the Strategy. In particular, submissions were welcomed from Autistic and Neurodivergent people and their families, friends, representatives, and key supporters.

Fifty-one responses were submitted; 25 were made through the online EUSurvey platform, 3 were made using the easy-to-read questionnaire, and there were 23 formal submissions. Submissions made via the EUSurvey platform were anonymous unless the respondent provided information about their personal circumstances in their response. In some cases, the author of this report used information provided in responses via the EUSurvey platform to categorise the responses.

[3] The National Disability Inclusion Strategy ended in December 2022 but was still in effect when the consultation was carried out.

Thirty-nine percent of the submissions were from Autistic and Neurodivergent people. This includes submissions from individuals, groups, alliances, and representative organisations of and for Autistic and Neurodivergent people.[4]

Nineteen percent of the submissions were from professionals working primarily in the education and health sectors. All of these respondents were providing supports and services for Autistic and Neurodivergent people. These submissions were from both individuals and professional representative organisations. This included education/training personnel; occupational therapists; speech and language therapists; psychologists; and teachers.

Eighteen percent of the submissions were from parents of Autistic and Neurodivergent people, mainly parents of children and young adults. This includes submissions from both individual and groups of parents and from parent-led organisations.

Fifteen percent of the submissions were from an unknown source (all of which were anonymously submitted online though the EUSurvey portal).

Five percent of the submissions were from not-for-profit and voluntary disability organisations. Some of these provide direct supports and services for Autistic people and their families, and one was an umbrella organisation representing the interests of people with disabilities and charitable organisations established to assist them.

Four percent of the submissions were from statutory agencies with specific statutory remits in relation to disability.

Eighty percent of the submissions responded under all eight questions in the questionnaire. Others only responded to certain elements of the questionnaire, and some provided comprehensive and detailed responses on particular issues.

Ninety-five percent of the submissions responded to the question of language and terminology.

Ninety percent provided examples of innovation across a range of areas.

Overall, all of the submissions highlighted the barriers and challenges that Autistic and Neurodivergent people experience. All submissions made suggestions for what should be included in an Autism Innovation Strategy, and there were some suggestions regarding the process for development, implementation, and the monitoring of the Strategy's progress.

4. What people told us about language

[4] The breakdown of responses is based on information provided in submissions and the assessment of the author of this report.

The clear message that came through the submissions is the preference for the identity-first term 'Autistic person', rather than 'person with autism'.

It was also noted that many Autistic people use the word 'Autistic' with an initial capital letter. This is because they do not see autism as a solely neurodevelopmental disability or a different neurotype, and because there is also an Autistic community that Autistic people identify and engage with, with a distinct identity and culture that they can participate in:

> "I'm autistic and I like identity-first language like this. I'm Autistic in the same way that I'm kind, intelligent, sensitive, and a bit impatient. You can't separate me from my Autism because it's part of me and my personality. It's not an add-on condition like my depression or eating disorder are for example. Those things I consider illnesses, but Autism is not an illness." (Submission from Autistic person)

> "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' [and] '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." (Submission from Disabled Persons Organisation)

> "We recommend honouring the widely expressed preference amongst Autistic people of identity-first language. This is in line with recent updates from the National Institute for Health and Care Excellence (NICE) [in the United Kingdom]." (Submission from professionals)

Several submissions highlighted the impact that language has on Autistic and Neurodivergent people. They stressed the need for neuro-affirmative language; that is, language based on the social model of disability. Such language affirms the positive contributions that Autistic people can make in a community and does not focus on deficits.

The following are examples of what some described as 'dated terminology' and language that should be avoided:

- 'High-functioning', 'low-functioning'; 'mild/moderate/severe'
  This was described as 'deficit-based' language in describing the autism experience. It is language rooted in the medical model of disability and wrongly implies that Autistic people do not require supports at certain times in their lives.

- 'Autism Spectrum Disorder' (ASD); 'disorder'

The submissions clearly articulated that Autistic people do not see themselves as 'broken' or 'having a disorder' simply because they have a different way of thinking and looking at 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." (Submission from Disabled Persons Organisation)

- 'ASD Unit'/'ASD Class'
  Some raised the point that for Autistic people and families, the word 'unit' implied a clinical setting and that Autistic children needed to be separated and segregated from mainstream education. They pointed out that this is not true, as Autistic children were also in mainstream classes:

  "Within health and education, it would be beneficial to move away from harmful labels of 'ASD class' or 'ASD unit' which pathologise children as 'disordered' to themselves and their peers. It is simply an Autism class/class for autistic learners." (Submission from Statutory Organisation)

Several of the submissions stressed how important it is that the language used to refer to Autistic people or the wider Autism community should always be guided by Autistic people themselves. It is also important that it continuously evolves to reflect the increasing diversity of the community.

Additionally, it was suggested that there is a need to review public sector information, literature and policy documents that are in the public domain with a focus on using empowering language and terminology preferred by Autistic and Neurodivergent people. In this regard, there were some specific observations and comments about the Autism Innovation Strategy and the importance of hearing the voice of all Autistic people:

"First and foremost. Please please, include Autistic voices! You cannot discuss and decide strategies that will directly impact Autistic people without considering their voices. Remember, you need a variety of their voices including from non-speakers. Seek neurodiversity affirmative approaches and for that you must listen to the community directly. That's why having their voices included is so important." (Submission from survey platform)

"The documentation to date referred to 'people with autism' all through which is alienating to most Autistic people and indicates we are already 'othered'. Worse was 'people with neurodiversity'. There is no such thing." (Submission from Autistic person)

> "Language that perpetuates ableism, pathologises Autism or portrays a deficit-based view of Autism has no place in an inclusive and respectful Autism [Innovation] Strategy." (Submission from Autistic professional)

5. What people experienced as barriers and challenges in their daily lives

All submissions highlighted a range of barriers and challenges that Autistic and Neurodivergent people face in their daily lives. Sections 5.1 to 5.7 outline examples of the issues raised by respondents.

5.1 Communications

Submissions emphasised that there is a lack of:

- Access to robust forms of communication for all non-verbal or minimally speaking Autistic people
- Access to public services for this cohort of Autistic people where the only means of communication is verbal; for example, in services where appointments can only be made by phone, and
- Consideration of communication styles and the communication profiles of Autistic people when seeking information from them:

> "Regrettably, the expressed goal of most therapies offered to autistic people in Ireland is to make us 'indistinguishable from [our] peers'. This often leads to an emphasis on using verbal speech and active discouragement of any communication which is viewed as not 'typical', denying the autistic people agency." (Submission from Autism Organisation)

> "Assisting service providers in becoming better educated on what Autism actually is, making it normal to listen to us and recognise that we are experts in ourselves. Treating us with respect. Recognising that our way of communicating may not be defective but simply different." (Submission from Autistic person)

5.2 Data

The 2018 Department of Health report *Estimating Prevalence of Autism Spectrum Disorders (ASD) in the Irish Population: A review of data sources and epidemiological studies* highlighted the need for more accurate data on autism prevalence.[5] Several submissions to the public consultation also highlighted this need. Not having data on

[5] Department of Health (2018) *Estimating Prevalence of Autism Spectrum Disorders (ASD) in the Irish Population: A review of data sources and epidemiological studies*. Available at: gov.ie - Reports on the prevalence of autism in Ireland and a review of the services for people with autism (www.gov.ie)

the actual numbers of Autistic people at any given life stage impacts on planning for services required and creates barriers for Autistic people in accessing the services they need. Examples given included:

- Challenges around the provision of special school and class places, which highlights the difficulties a lack of accurate data can create;
- No robust data sharing between services and the impact this has on Autistic people in progressing through different stages of development, from child to teenager to adult to independent living; and
- Lack of data on Autistic women and girls in areas such as gender violence, eating disorders, and pregnancy:

  "Without having the actual number of Autistic people, how can services be budgeted for? We know that people assigned female at birth have been under-diagnosed. We know that the intersection with LGBTQIA+ [lesbian, gay, bisexual, transgender, queer, intersex, asexual +] is huge." (Submission from Autistic person)

  "There needs to be confirmation of the exact numbers of autistic people at any given life stage such as in school, leaving school, those in need of Day Services, [and] those in need of specific Housing supports, so that state agencies like the HSE [Health Service Executive], National Council for Special Education and Local Authorities can plan better." (Submission from Autistic person)

5.3 Education

Some respondents highlighted the lack of:

- Sufficient specialist places/classes for Autistic children in primary and secondary schools
- Sufficient specialist autism-specific training available to primary and secondary school staff
- Access to appropriate supports, such as waiting lists for autism classes/schools, and for support from disability services, and
- Access to inclusive summer school programmes for Autistic children who require very substantial support.

Other matters of concern raised by respondents which disproportionately affect Autistic pupils and impact their experiences with their education include:

- The use of reduced timetables
- Suspensions and expulsions
- The use of seclusion, and
- Unregulated restrictive practices.

Several submissions had serious concerns with, and expressed opposition to, certain therapies and practices, with some calling to ban the practice of Applied Behavioural

Analysis and associated therapies and practices. These therapies approach autism as a deficit and make Autistic people conform to neurotypical norms:

> "Currently compliance-based interventions are being offered throughout Ireland's health and education services. This is incongruent to the Autistic community's view on such services. Such compliance-based practices which attempt to fundamentally change the Autistic individual to look or perform more like a neurotypical person or hide their authentic Autistic selves to make them appear less Autistic to the external world have been shown to be harmful to Autistic people… and lead to strengthening behaviours, such as masking (acting the role of a neurotypical person) or camouflaging (hiding external Autistic features to blend in and appear less Autistic). An increasing amount of research is emerging that shows that both masking and camouflaging are factors in many negative outcomes such as being a barrier to authentic connection and self-awareness, low self-esteem, loneliness, misdiagnosis, reduced mental wellbeing, fatigue, burnout…depression and suicidality." (Submission from professionals)

5.4 Employment

Respondents highlighted the lack of:

- A clear pathway out of education into employment for young Autistic adults, and
- Awareness among employers of autism-friendly work practices.

Other barriers to finding work included Autistic people having negative experiences of interview processes and testing methods.

Some respondents raised the issue that even when Autistic people do find work, there is still significant stigma around autism, which can negatively shape an Autistic person's experience at work and pose barriers to being supported at work.

One submission cited a finding in the report *Autism in the Workplace: Creating opportunity for autistic people*,[6] which was 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…less than 10% of people felt confident enough in their colleagues' knowledge of Autism to disclose or otherwise be open about being Autistic…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." (Submission from Disabled Persons Organisation)

[6] AsIAm and IrishJobs.ie (2021) *Autism in the Workplace: Creating opportunity for autistic people*. Available at: Creating opportunity for autistic people - IrishJobs Recruiter News

5.5 Equality

Respondents raised issues relating to equal status and equitable access to services, including:

- Perpetuating the stigmatisation and marginalisation of Autistic people in Ireland through the continued use of the medical model for service provision;
- Inadequate consideration of the needs of Autistic people who arrive in Ireland seeking international protection; and
- No publicly funded autism assessment or intervention for adults who are questioning their Neurodivergence:
  "Anyone who can afford to is paying private clinicians for this service. This creates a system where those who can pay can get a diagnosis and therefore access to (for example) reasonable accommodations in the workplace, whereas those who cannot pay are discriminated against in this regard. This raises issues of equity of access to service and is a breach of human rights." (Submission from professionals)

5.6 Health

Many respondents highlighted the lack of:

- Access to appropriate supports – for example, waiting lists for autism classes/schools and for disability services
- Early intervention services and timely assessments for Autistic children;
- Access to services and supports, including speech and language therapy, occupational therapy, and psychology;
- Sufficient multidisciplinary resources in place to provide necessary diagnosis, early intervention, and other appropriate therapies and supports
- Shared care or linking between Child and Adolescent Mental Health Services (CAMHS), primary care, and disability services
- Public health assessments and support for Autistic adults and how it impacts on other services they may be accessing, such as the National Gender Service
- Inpatient care settings that are adapted to reduce sensory overload
- A centre of excellence for Neurodivergence in Ireland
- Support for parents of Autistic children post-diagnosis of autism:
  "…helping families through that time and helping them with their children's difficulties [to] make [this] less of a stressful time, there's no one there to navigate their diagnoses [and] we are left in the dark to figure out what they need so we go and try [to] find it ourselves [by] talking to other parents." (Submission from parent)
- Access to adequate mental health and occupational therapy support:
  "Many people (myself included) diagnosed with Autism as an adult have a long history of complex mental health issues due to lack of support growing up. I've basically bankrupted my family over the past years (since age 12) paying

> privately for psychiatrists, psychologists, etc." (Submission from Autistic person)

5.7 Income adequacy

The issues of income adequacy and the risk of Autistic people and/or their families falling into the 'poverty trap' were raised by respondents as barriers for Autistic people's participation and inclusion in Irish society. Respondents highlighted the extra spending needs that people with a disability face in their day-to-day lives that others in society do not face:

> "The cost of disability has been recently identified as having a considerable cost on 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." (Submission from Disabled Persons Organisation)

Some of the issues raised around income adequacy included the following:

- Many Autistic people and their families rely solely on social protection from the State as a key source of income.
- Social protection payments do not cover the extra costs that Autistic people and their families face.
- Assessments for disability payments are very medicalised, basing their findings solely on a person's perceived functional capacity.
- The means-testing system has the effect of pushing people and families into poverty:

  > "[This] 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'…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." (Submission from Disabled Persons Organisation)

6. What people said about innovation, empowerment and awareness-raising

Respondents provided a range of examples of innovation in ways in which Autistic people accessed services and were supported, and good practice in empowerment and awareness-raising. In answering these questions, some of the respondents made

suggestions about what they see as good practice and what they would like to have in place as opposed to examples of what is currently in place.

Some pointed out that while these examples may well be good practice, it is important to have some form of process to establish how effective such practices and/or innovative initiatives have been in the lives of Autistic people themselves. In this regard, it was suggested that it would be helpful to include a review of further research on a sample of these good practices, so that lessons could be learned in order to enhance the positive impact on the lives of Autistic people:

> "Any innovation needs to be evaluated, and go through an iterative process where it is developed in response to feedback and experience." (Submission from professional)

The suggestions fall into two main categories: generic/universal approaches (see Sections 6.1–6.3) and specific initiatives (see Section 6.4).

6.1 Innovation

The following suggestions were made by respondents in relation to innovation.

Autistic people and innovations

> "Innovations need to have Autistic people involved in their selection, design, implementation, and evaluation." (Submission from Autistic professional)

Community

With regard to using the network of Connected Hubs nationwide to promote autism-friendly practices, one submission read:

> "We have approximately 300 hubs situated throughout the country, some in the most remote and isolated communities in the State which is a huge advantage for service coverage. These units are normally community or non-profit run and are modern, well serviced facilities with civic responsibility as one of their core values. They operate with 24/7 access. By promoting a silent room with easy word and access platforms within hubs that will [offer] an open door and welcoming gateway for autism support groups, guardians and family supporters, children and young adults alike." (Submission from survey platform)

Disability services

> "[Promote] alternative models of care to those currently provided in traditional day service centres and in the wider areas of respite/home support." (Submission from Disability Organisation)

Education

"More flexibility in catering for neurodivergent children (instead of insisting upon a diagnosis to enter an ASD class) such as a neuro-profile/passport for each child, could ensure that the child has input into how they are perceived by others and taught by staff." (Submission from parents)

"All and any support offered to autistic people should be neurodiversity-affirmative, including a total communication approach being applied, with adults accepting and validating all communicative attempts by the autistic learner, be that via spoken word, a device, or vocalisations." (Submission from Statutory Organisation)

"Clear centralised reporting on school places and what is available and where." (Submission from Parents)

"Parents [should] be included in discussion or modelling on any key changes in Education policy for Additional Educational Needs (AEN) of children and a clear educational policy and plan to address the shortage of AEN school places in Ireland [is needed]." (Submission from parents)

"New models of support [should be provided] to those young autistic people at vulnerable stages of transition towards the end of secondary school." (Submission from Disability Organisation)

Environment

"Use the design principles of universal design from the start." (Submission from professionals)

"Adapting how we can address the suitability of environments, conduct sensory Audits of spaces using Autistic consultants to do so." (Submission from professionals)

"Design for neurodiversity, which means designing a collection of environments and spaces that suit the diversity of humans." (Submission from professionals)

Health

"Trained Autism Support Worker in medical settings to help navigate/advocate for rights/sensory preferences." (Submission from survey platform)

"Adequately funded clinical teams for robust assessment and post-diagnostic support pathways." (Submission from Autism Organisation)

Research

> "There is a need for examples of innovative co-produced and participatory research to inform policies and strategies. This presents an opportunity for co-production of research by Neurotypical and Neurodivergent researchers." (Submission from professionals)

6.2 Empowerment

Respondents made a range of suggestions regarding the empowerment of Autistic people in the areas outlined throughout Section 6.2.

Assistive technology

> "[The] introduction of new technology to help [us] to communicate." (Submission from Autistic person)

> "For non-speakers, please do have robust communication options, such as high-tech AAC [Augmentative and Alternative Communication], ISL [Irish Sign Language], spell to communicate with the use of a letter board. Do not use ABA [Applied Behaviour Analysis] or PECS [Picture Exchange Communication System]. Presume competence of Autistic people." (Submission from survey platform)

Community inclusion

> "Assess and address barriers to education/employment and community integration." (Submission from survey platform)

> "Review national guidelines on Universal Design to ensure all public buildings and spaces are accessible for Autistic people." (Submission from Disabled Persons Organisation)

Consultation and engagement with Autistic people

> "Collaborate with Autistic groups. Don't just rely on Autistic charities to give you a narrative, even those with Autistic members cater more for parents and rarely reflect our views. Communicate directly with our community rather than through charities. Also include the voices of non-speakers." (Submission from Autistic person)

> "Be empowering by sharing power, dissolving power, speaking to many, [and] involve[ing] many, there is so much diversity in the Autistic population… to make change nationally good practice needs to be inclusive and accessible to that diversity. Foster collaboration. Consult different people, don't rely on the same group of Autistic people all the time. Consult groups you never talked to before from different backgrounds, different races, different occupations,

different ethnicities, different societal groups, different ages etc." (Submission from professionals)

"It is essential that any Autistic representation comes from multiple sources to ensure that many Autistic viewpoints and voices are heard and considered. A variety of stakeholder groups should be consulted regarding anything to do with Autism… Ireland has many Autistic professionals including teachers, psychologists, speech and language therapists, social workers, occupational therapists and healthcare professionals who can and should be recruited to devise and deliver any training which comes from this strategy. Autistic researchers should be given the opportunity to be involved in production and co-production of any research on the topic of the Autistic experience in this country." (Submission from professionals)

"Consult with Autistic people on education and employment policies." (Submission from professional)

"Involve Autistic people in policy making." (Submission from survey platform)

Education

"Include Additional Educational Needs children on school councils in all schools (student voice)." (Submission from parents)

"Each school should encourage integration. Best practice is that children in special classes have the opportunity to integrate with their peers. The integration policy and how it is working in practice should be reviewed." (Submission from parents)

Employment

"Help autistic people to stay in employment by mandating (or promoting through tax breaks) working from home options, and autism-friendly workplaces, as well as part-time or reduced hours options." (Submission from Autistic person)

"Flexibility regarding work systems would undeniably allow autistic people to better access supports and services." (Submission from parents)

"Development of community-based work experience for autistic teens/young adults." (Submission from survey platform)

Governance

"Autistic and neurodivergent people should have the opportunity to be appointed to the Boards of Directors of disability charities and service providers. It should be compulsory for all HSE funded service providers to appoint

disabled people (including service users) to their Boards of Directors." (Submission from Autistic person)

"Support Autistic people to become Board members of State Boards." (Submission from professional)

Understanding autism - training

"Non-speaking Autistic people, and others without oral speech, are among the most marginalised and vulnerable people in our society. Access to AAC can lead to an increased quality of life, less dependency on social services and increased social inclusion." (Submission from Disabled Persons Organisation)

"Non-speaking does not mean non-thinking…What do we need? [A] dedicated body whose aim is to support and advance the rights of non-speakers and those with speech-related disabilities. Better training in AAC for Speech and Language Therapists [and] training for teachers." (Submission from parent)

"[Provide] training from an Autistic perspective [and] include Autistic voices. One may be overwhelmed with sensory input or need movement breaks and that should be okay." (Submission from survey platform)

"The provision of workshops on topics such as advocating for yourself and your peers, the Inclusion Ireland/IHREC [Irish Human Rights and Equality Commission] Media and Human Rights workshop to be rolled out to Autistic people." (Submission from Autistic person)

"Using identity-first language as standard is much more empowering for Autistics." (Submission from Autistic person)

6.3 Awareness-raising

Respondents made a number of suggestions regarding awareness-raising, which are outlined throughout Section 6.3.

Autism: understanding

"Awareness means only being 'aware' that Autism exists. This rarely translates into 'inclusion' and 'understanding' of Autistic people and their families. The 'image' of Autism, which the 'average' member of the public may see, is that of a young (white) boy having a meltdown in a busy supermarket or the (white) adult man who is a maths genius." (Submission from Autistic person)

"Autism does not discriminate on the basis of race, ethnicity or language. Autistic people can have other disabilities. Autistic people can be LGBTQ+." (Submission from Autistic person)

"We must move quickly on from awareness and into proper understanding and knowledge, awareness only does so much[;] it's the tip of the iceberg and doesn't really help. Many people are aware, but they're still unkind." (Submission from Autistic person)

"[Autistic people] need compassion and understanding and practical supports. Not awareness to be honest. Embedding a strengths-based, neuro-affirmative approach in all aspects of clinical/teacher training, workplace neurodiversity initiatives [and] genuine accommodations for students and adults in workplaces." (Submission from Autism Organisation)

"Training at a national level [should focus on] moving from awareness to acceptance, through building understanding and skills." (Submission from Statutory Organisation)

Community

"Although most of our community prefer acceptance-focused campaigns, if raising awareness make sure you've checked [that] your material is up to date and autistic approved. Most awareness campaigns cause more harm than good, reinforcing outdated stereotypes (for example, light it up blue)…Avoid language about cures. Avoid person first language. Involve autistic self-advocates. Avoid functioning labels, we're not more or less autistic." (Submission from Autistic person)

"AUTISTIC PARKING SPACE signs would shake a neurotypical Ireland that already has awareness but not acceptance. Acknowledgment from the government that Autism is an invisible disability would encourage change and understanding. Other countries accept Autism as grounds for disabled parking but not Ireland, is this because politicians don't believe it is a disability? If specific spaces were allocated for Autistic people, then this would send a far stronger message to society than any campaign. Individuals telling their story is of enormous support to autistic people, families, educators and therapists. Normalising neurodivergence and acceptance of neurodiversity in society is huge. Prejudice against brain difference is pervasive in society." (Submission from Autistic person)

"The Autistic community should have an equal opportunity to enjoy Ireland's culture, heritage, sports, creative arts, and music. Social isolation and loneliness are a major issue for autistic people and their families. It is imperative

to work towards specific autism community inclusion programmes and promote meaningful relationships and social opportunities in order that autistic people are met with greater acceptance in Irish society." (Submission from professional)

"Support local groups and organisations of Autistic people to come together with their local stakeholders of statutory and community-based support to deliver greater awareness-raising and inclusion at local level." (Submission from Disability Organisation)

"Encourage inclusion in communities via neuro affirmative education/training and acceptance." (Submission from survey platform)

"Government grants for Sport Clubs should include criteria on the clubs' policy regarding the support of special needs people in their clubs." (Submission from parents)

"Use social media extensively to raise awareness of Autism and to promote positive stories around Autism. Some centres also run awareness courses for businesses to enhance the employment opportunities for autistic people." (Submission from Disability Organisation)

Education

"Learning about Autism needs to start in schools – a curriculum such as LEANS [Learning About Neurodiversity at School] should be implemented in all schools. Teachers need much more training from Autistic people." (Submission from survey platform)

Public services

"Government service providers could be educated on what Autism is and trained in how to connect, communicate [with] and support us." (Submission from Autistic person)

Health and education services

"Brochures in GP offices about common neurodivergences. I had no idea how to get a diagnosis and it was really infuriating to have to hunt down people online with no help." (Submission from Autistic person)

"The roll-out of comprehensive Autism awareness training for all adult mental health services nationwide. This should focus specifically on clinical issues frequently seen in adult mental health services, such as mood disorders, eating disorders and gender diversity. The training should outline how Autism intersects with these co-occurring conditions, impacting their clinical

presentation with practice considerations for assessment and intervention processes." (Submission from survey platform)

"Healthcare and education providers should promote Autism acceptance through rejection of practices/approaches which can be considered to be in direct conflict with acceptance of neurodiversity. This would involve transparent and open discussions with service users and their families throughout the journey from pre-diagnosis, during diagnosis and post-diagnosis and also moving throughout the lifespan, supporting the Autistic individual and their authenticity and providing education to those around the Autistic individual at the macro and meso levels and not solely at the micro level." (Submission from professionals)

"Autism acceptance should be promoted by the HSE through specific training on the neurodiversity affirmative paradigm shift and model for practice, to be delivered to all tiers of healthcare. Similarly, the Department of Education and National Council for Special Education should provide specific training on the topic of neurodiversity affirmative practice... This training should be delivered to all tiers of education and all public health services. 'All tiers' should include management level with respect to both healthcare and education. These trainings should be delivered by Autistic people and on a recurring basis to account for staff turnover. Co-production and co-delivery of training can also be viewed as viable options (for example, autism Level Up." (Submission from professionals)

6.4 Specific examples of innovation and good practice

The extracts provided in Section 6.4 are taken from individual submissions in which people cited examples of what they deemed to be good practice in a variety of settings.

Advocacy

"The Rehab Group has four advocacy structures that serve to empower people [they] support, including the more than 20% of people in [their] services who are Autistic. The central aim of these structures is to ensure that the voice of people is heard both inside and outside the organisation." (Submission from Disability Organisation)

Assistive technology

"TU Dublin [Technological University Dublin] has created a new assistive technology repository. The repository is an online resource that aims to raise awareness of the forms of assistive technology that are available and aims to teach staff and students how to work with it." (Submission from Disabled Persons Organisation)

Education

"The *Autism Good Practice Guidance for Schools*[7] suggests ways in which peers can be educated on autism awareness." (Submission from Statutory Organisation)

"UCD [University College Dublin] and NCSE [National Council for Special Education] provide the first national SNA [Special Needs Assistant] training programme and have a dedicated module on autism."[8] (Submission from Statutory Organisation)

"Middletown Centre for Autism provides training and support for parents and teachers of autistic learners. Their website has many resources."[9] (Submission from Statutory Organisation)

Empowerment

"The One Stop Shop model employed in Scotland is an accessible way to receive support – from assessment, through post-assessment Autism supports, supports with service accessibility in general, and opportunities for peer connection." (Submission from Autistic person)

"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." (Submission from Disabled Persons Organisation)

"Follow international best practice, whether from the Middletown Centre [for Autism], National Autistic Society [in the] UK, AsIAm, [and] many more." (Submission from parents)

"The DFI [Disability Federation of Ireland] led Independent Living Skills Project [is a good example]. Established in the west of Ireland, this project established a formal space of regard for previous, and historic well-formed relationships between voluntary disability service providers to come together with every Local Education and Training Board and Local Development Company in the region to support people with disabilities to access health and well-being training within

[7] Department of Education (2022) *Autism Good Practice Guidance for Schools: Supporting Children and Young People*. Dublin: Government of Ireland. Available at: https://www.gov.ie/en/publication/8d539-autism-good-practice-guidance-for-schools-supporting-children-and-young-people/

[8] UCD School of Education (n.d.) *National Training Programme for Special Needs Assistants*. Available at: https://www.ucd.ie/education/study/specialneedsassistants/

[9] Middletown Centre for Autism (n.d.) *Middletown Centre for Autism*. Available at: https://www.middletownautism.com/

their local community. This project can readily be replicated for supporting the specific goals of independence and capacity building for people with Autism in another region." (Submission from Disability Organisation)

"Thriving Autistic is an example of good practice in providing autistic support services in Ireland, who should be consulted regarding the developing neural-affirmative adult supports alongside Autistic-led organisations and Disabled Persons Organisations." (Submission from Disabled Persons Organisation)

"The Level Up program[10] is an excellent programme from the [United States of America]…supporting communities to move from awareness [to] acceptance, appreciation, empowerment and advocacy. Awareness at this stage is such a low bar to be striving towards, we need to be ambitious for the neurodiverse community." (Submission from parents)

"Develop and adapt pre-diagnostic supports using a NeuroAffirmative model [such as the] *Am I Autistic?*[11] example of pre-diagnostic supports for adults." (Submission from professionals)

Environment

"An example of innovative practice and research is the Trinity College Dublin Sense Project."[12]This aims to make Trinity more inclusive by reviewing and improving new and existing spaces, building sensory awareness and delivering specialist supports to students who experience barriers to managing and adapting [to] the sensory environments of college. (Submission from professionals)

Health

"[There is] innovative work from [the] National Development Team for Inclusion (NDTi) in the UK using Autistic consultants to review and advise on hospital environments/wards and CAMHS inpatient units."[13] (Submission from professionals)

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[10] Autism Level UP! (n.d.) *Autism Level UP!* Available at: https://autismlevelup.com/

[11] Boué, S. (2022) *Am I Autistic?* Birmingham, UK: BOM (Birmingham Open Media). Available at: Am I Autistic? - BOM

[12] Trinity College Dublin (n.d.) *TCD Sense*. Available at: https://www.tcd.ie/disability/services/tcdsense.php

[13] National Development Team for Inclusion (n.d.) *"It's Not Rocket Science" Sensory Friendly Wards Principles List*. Available at: Sensory Friendly Ward Principles - NDTi

National Development Team for Inclusion (2020) *"It's Not Rocket Science": Considering and meeting the sensory needs of autistic children and young people in CAMHS inpatient services.* Bath, UK: National Development Team for Inclusion. Available at: "It's Not Rocket Science" - NDTi

"Community-based model[s] of respite which speak to the needs and will and preference of autistic children and the support needs of their families[;] e.g. [the] Bluestack Special Needs Foundation."[14] (Submission from Disability Organisation)

Promoting understanding of autism

"The NDA [National Disability Authority] was assigned a number of actions under the Programme of Actions on Autism [as part of the] National Disability Inclusion Strategy 2015… [It] developed the following guidance targeted at sectors identified in the mapping and consultation [process] which included adults with autism:

- NDA (2018) *Assisting People with Autism: Guidance for Justice Professionals [in communicating with people with autism]*
- NDA (2018) *Assisting People with Autism: Guidance for Local Authority Housing Officers*
- NDA (2018) *Assisting People with Autism in Employment: Guidance for Line Managers and HR Professionals*
- NDA (2017) *Models of Good Practice in Effectively Supporting Adults with Autism [without a Concurrent Intellectual Disability, Living in the Community]* (Submission from Statutory Organisation)."

"Our community group, Neurodiversity Sandymount, have distributed a kids' story to local schools explaining neurodivergence from the child's perspective, which was very well received in the village and spawned art competitions etc. in schools. Most of our children are also ADHD, dyslexic, etc and we are raising awareness of all neurodiversity by educating children first and foremost. By getting parents involved at this level, we are trying to change people's attitudes to having neurodivergent children in their schools – to show that our children are not scary or unmanageable but rather just children with different brains. We are all different and if people stop thinking of them and us, this should result in an inclusive community." (Submission from parents)

"Co-production is key to good practice in this area also. The Disability Service at Trinity College Dublin has developed a programme of staff neurodiversity training and awareness in collaboration with autistic students to ensure a good understanding of needs and barriers (physical, social and institutional) to student participation." (Submission from professional)

"Initiatives such as DCU's [Dublin City University's] Autism Friendly University have helped to raise awareness of Autism amongst both staff and students,

[14] Bluestack Special Needs Foundation (n.d.) *Bluestack Special Needs Foundation*. Available at: https://www.bluestackfoundation.com/supports-services

helping to create a more inclusive and accessible educational environment for people with Autism." (Submission from survey platform)

Research

Examples of innovative practice and research include:

- People, Place, Policy and Practice for Play[15] [P4Play]. This is a European Doctorate Programme for Occupational Therapists… its aim is to deliver innovative play solutions to benefit the health and wellbeing of diverse children, families and communities. (Submission from professionals)
- The National Council for Special Education's *Evaluation of the In-School and Early Years Therapy Support Demonstration Project*. This innovative project involved the development and implementation of a speech and language and occupational therapeutic support model for mainstream schools, special schools and early years' settings.[16] (Submission from professionals)
- *Second Level Education and Autism Spectrum Disorder: An Exploration of Peer, Parent and Teacher Experiences*.[17] (Submission from professionals)

Support services

"An example of good practice in [Third Level Education] is [the] neuro-affirmative Occupational Therapy Support Service within Trinity College Dublin."[18] (Submission from professionals)

"Acknowledging [the] intersectionality of autism and gender identity… [and the] need for models of shared care/joint work [is important]."[19] (Submission from professionals)

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[15] UCC Institute for Social Science in the 21st Century (n.d.) *P4Play: People, Place, Policy and Practice for Play*. Available at: www.ucc.ie/en/iss21/researchprojects/researchprojects/p4play/

[16] Lynch, H., Ring, E., Boyle, B., *et al.* (2020) *Evaluation of In-School and Early Years Therapy Support Demonstration Project*. Research Report No. 28. Trim, Ireland: National Council for Special Education. Available at: Evaluation of the in-school and early years therapy support demonstration project (ucc.ie)

[17] Cremin, K., (2018) *Second Level Education and Autism Spectrum Disorder: An Exploration of Peer, Parent and Teacher Experiences.* Available at: Second Level Education and Autism Spectrum Disorder: An Exploration of Peer, Parent and Teacher Experiences (tcd.ie)

[18] Trinity College Dublin (n.d.) *Occupational Therapy (OT) Support*. Available at: https://www.tcd.ie/disability/services/OT.php

[19] Moore, I., Morgan, G., Welham, A., *et al.* (2022) 'The intersection of autism and gender in the negotiation of identity: A systematic review and metasynthesis', *Feminism & Psychology*, 32(4), pp. 421–442. Available at: https://doi.org/10.1177/09593535221074806

7. What people suggested for inclusion in the Autism Innovation Strategy

> "This Strategy should bring together a new vision and go beyond only addressing emergency situations or service shortfalls and should look at how the rights of Autistic people can be upheld and how understanding, inclusion and participation can be promoted at every stage of life." (Submission from Disability Organisation)

7.1 Overarching perspective

A number of issues were raised in the submissions, such as about the role Autistic people will have in the development, monitoring and review of the Strategy; the diversity of Autistic people; and who the Strategy is for.

Central to the respondents' suggestions is that the Autism Innovation Strategy should recognise and uphold the following concepts:

- The Strategy should recognise Autistic people's stated preference for identity-first language.
- The Strategy should take a participatory approach whereby Autistic people are involved in decision-making, implementation and evaluation.
- Co-production and co-design with Autistic people should be part of the Autism Innovation Strategy and delivered both in process (how the Strategy is designed) and in the outputs (ensuring that work is delivered).
- Participation and co-design should be embedded in the proposed actions of the Autism Innovation Strategy in the areas of research, policy and service provision.
- A clear evaluation plan should be an integral part of the Strategy and the findings of the evaluation should inform future developments and be shared widely with Autistic people in accessible formats.
- The Strategy needs to acknowledge that 'one size does not fit all' and needs to reflect the experience of Autistic people across many different contexts:

> "Autism does not just affect those who are advocates and able to articulate. The Autism Innovation Strategy must facilitate engagement and ensure integrity of regard for the entire population of autistic adults and children in Ireland, not just the lived experience of those who can directly communicate their experience. Supporting the significant, complex, holistic needs of all people who are autistic, including those who may live in supported care settings and who may be nonverbal, with co-existing conditions, along with their families must be part of this strategy in a deliberate, and thoughtful way which gives voice to the person, their family and the service specialist who walks alongside them." (Submission from Disability Organisation)

- Respondents also stressed that the Autism Innovation Strategy should recognise the convergence of intersectional barriers for Autistic people:

  > "Include asylum seekers. The [UNCRPD] assures us of access to all governmental agencies. I have not seen this in action since entering asylum in November of 2021. No vulnerability assessment has been offered to me, so the people in charge of placing me in housing have no idea of my mental and physical limitations. I am lucky to be able to advocate for myself, but it is still overwhelming. I am living in terror." (Submission from Autistic person)

7.2 Human rights approach

Several of the submissions highlighted that the Autism Innovation Strategy offers an opportunity to 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 self. Respondents identified a number of issues which they want to be addressed within the Autism Innovation Strategy, as outlined below.

Social model of disability

Some respondents emphasised the importance of moving from the medical model of disability to the social model of disability with a focus on removing the physical, social and attitudinal barriers which restrict people from exercising their right to access services and from living an ordinary life in the community:

> "It is therefore important in the context of the social model of disability that the Autism Innovation Strategy is seen to focus on building the knowledge base and capacity to further remove these barriers faced by Autistic people rather than being perceived to be focusing on a particular disability." (Submission from Statutory Organisation)

Respondents emphasised the importance of a more holistic and neuro-affirmative approach to disability assessments and providing support, in line with the social model of disability and the UNCRPD:

> "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." (Submission from Disabled Persons Organisation)

A key concern for some respondents is to examine the practices of isolation, seclusion and restraint of disabled people where such practices are used by schools and care services across Ireland:

> "We are extremely concerned to see that the issues raised on the use of isolation, seclusion, and restraint; practices which are disproportionately used against intellectually disabled, neurodivergent, and ethnic minority children [have] mostly been ignored. It poses a risk to their right to equal access to education as articulated under Article 24 of the UNCRPD." (Submission from Disabled Persons Organisation)

> "We call for the Autism Innovation Strategy to explicitly ban the use of such interventions." (Submission from Disabled Persons Organisation)

Respondents also highlighted the importance of moving away from approaches which pathologise and aim to 'fix' or 'cure' Autistic people to fit into neurotypical norms. They suggested that assessments and interventions 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:

> "The long-term goal [is] the implementation of interventions which are person-centred and human rights compliant and the eradication of any practices which impinge on an individual's liberty, autonomy, dignity or right to be free of violence and cruel or degrading treatment." (Submission from Disabled Persons Organisation)

It was also suggested that there is a need for an ethical principles framework for reforming autism interventions focused "on the needs, wants and well-being of Autistic people rather than the preferences and assumptions of those around them." (Submission from Disabled Persons Organisation)

United Nations Convention on the Rights of Persons with Disabilities

Several of the submissions stressed that the work of the Autism Innovation Strategy should be framed within the context of the UNCRPD and Ireland's commitment to continuous advancement of its obligations under same. The rationale given for this was as follows:

- Aligning the actions contained in the Autism Innovation Strategy with the UNCRPD could facilitate the streamlining of monitoring and reporting mechanisms and reduce duplication for Government Departments.

- This alignment could also help to address the fact that many Autistic people also have other disabilities:
  "It is estimated that between a third and a half of Autistic people also have an intellectual disability.[20] About 70% of Autistic children are estimated to have a mental health co-morbidity.[21] Studies are also emerging of co-morbid disabilities for Autistic people as they age."[22] (Submission from Statutory Organisation)

There were also some suggestions regarding legislation, including:

- The ratification of the UNCRPD Optional Protocol
- Review of the Disability Act 2005, particularly regarding Part 2 and the issues with Assessment of Need
- Review of the Education for Persons with Special Educational Needs Act 2004, and
- The introduction of legislation in line with the European Charter of Rights for Persons with Autism, signed in 1996 by the European Parliament, which states that 'the rights of Autistic people should be enhanced, protected and enforced by appropriate legislation'.

7.3 How the Autism Innovation Strategy will align with other strategies

A number of issues raised by respondents in their submissions have to do with existing services and/or are contained in other strategies which the respondents want to be addressed in the Autism Innovation Strategy. Such issues included:

- Assessment of Need
- Early education and care
- Inclusive education, and
- Progressing Disability Services
- Programme of Actions on Autism

[20] Department of Health (2018) *Estimating Prevalence of Autism Spectrum Disorders (ASD) in the Irish Population: A review of data sources and epidemiological studies*. Available at: gov.ie - Reports on the prevalence of autism in Ireland and a review of the services for people with autism (www.gov.ie)

[21] Crowe, B. H. A. and Salt, A. T. (2015) 'Autism: the management and support of children and young people on the autism spectrum (NICE Clinical Guideline 170)', *Archives of Disease in Childhood – Education and Practice Edition*, 100(1), pp. 20–23. Available at: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4316840/

[22] Miot, S., Akbaraly, T., Michelon, C., *et al*. (2019) 'Comorbidity Burden in Adults with Autism Spectrum Disorders and Intellectual Disabilities–A Report from the EFAAR (Frailty Assessment in Ageing Adults with Autism Spectrum and Intellectual Disabilities) Study', *Frontiers in Psychiatry*, 10, p. 617. Available at: https://pubmed.ncbi.nlm.nih.gov/31607957/

Some respondents noted that these areas relate to issues that are not unique to Autistic people. However, there is an expectation that they do need to be progressed in order to address concerns raised frequently in the submissions.

Assessment of Need

Respondents highlighted the challenges posed by Part 2 of the Disability Act 2005:

> "The challenges posed by Part 2 of the Disability Act have had a significant impact on the capacity of services to provide intervention to children with disabilities, including children with autism." (Submission from Statutory Organisation)

> "Delays related to operating Assessment of Need under the Disability Act have meant that some families have faced lengthy delays in receiving a diagnosis of Autism which is still required to access certain supports (for example Special Schools and Special Classes) and many parents feel that a diagnosis is very important to them to help them understand their child's needs." (Submission from Statutory Organisation)

As stated in Section 7.2, some respondents called for a review of Part 2 of the Disability Act 2005 and of the Education for Persons with Special Educational Needs Act 2004, ideally in parallel. It has also been suggested that an action under the Autism Innovation Strategy could be to carry out research on systems of assessment and intervention for children with disabilities, including Autistic children, in other jurisdictions in order to inform a future review of Part 2 of the Disability Act 2005.

Another suggested action is for the development of a standardised approach to autism diagnostic assessments:

> "To ensure that scarce clinical resources are best utilised, a standardised approach to Autism diagnostic assessments (whether or not children are assessed under Part 2 of the Disability Act) should be agreed between the HSE and relevant professional bodies. In line with the HSE 2018 review of Autism services,[23] this should be a tiered approach to assessment whereby the intensity of a diagnostic process is determined by the complexity of presenting issues and clinicians' judgement." (Submission from Statutory Organisation)

Early education and care

A suggested action for the Autism Innovation Strategy is the need for a plan to build autism knowledge and capacity among early education and care professionals:

[23] Health Service Executive (2018) *Report of the Review of the Irish Health Services for Individuals with Autism Spectrum Disorders*. Available at: gov.ie - Reports on the prevalence of autism in Ireland and a review of the services for people with autism (www.gov.ie)

> "The 3 Year Evaluation of the AIM (Access and Inclusion Model) Programme is likely to prompt questions about the ongoing provision of Department of Education funded Early Intervention Classes and the remaining HSE funded special pre-schools, some of which autistic children attend. It is also likely that the evaluation report [of the AIM model] may have recommendations regarding Autistic children in mainstream early education and care." (Submission from Statutory Organisation)

Inclusive education

Several submissions raised issues regarding school places and school inclusion:

> "Recent years have seen a very steep rise in the number of special classes, many of them to meet the demand for special class places for Autistic children. Despite improvements, the process to estimate and plan for new special classes [in order to meet] demand has proved to be challenging." (Submission from Statutory Organisation)

> "The segregation between special and mainstream schools in the education system, reinforces [the] culture of difference and exclusion by denying opportunities for interaction that could develop awareness, tolerance and understanding at a formative age." (Submission from Disability Organisation)

> "There is an absence of evidence available to either support or refute the position that Autistic children have better social and education outcomes in mainstream or special classes." (Submission from Statutory Organisation)

> "All Autistic children should be able to experience an inclusive mainstream education." (Submission from Disability Organisation)

Some respondents also suggested that the Autism Innovation Strategy provides an opportunity to include some actions which could contribute to shaping the vision of inclusive education which would maximise the potential of Autistic children to progress through the school system on to further and higher education, training, and employment options that most suit them.

Progressing Disability Services

Several issues were raised in submissions with regard to the inadequacy of services and, in some cases, a total lack of services for Autistic children. The key factor underlying this is that even with the Disability Network Teams in place across Ireland, there is still a lack of capacity to meet demand, and several respondents raised the issue of inadequate resources.

It was suggested that an action around supply of therapists should be included in the Autism Innovation Strategy:

> "The need for more therapists has been demonstrated by previous work by the NDA,[24] the HSE with assistance from the NDA[25] and the Department of Health."[26] (Submission from Statutory Organisation)

> "Our number one recommendation [is] around the urgent development of a comprehensive workforce planning strategy to address the lack of therapists and clinicians." (Submission from Disability Organisation)

Programme of Actions on Autism

One submission noted that a Programme of Actions on Autism was developed under the National Disability Inclusion Strategy (signed off by the Cabinet Subcommittee on Social Policy in 2015). It should be noted that this Programme of Actions was developed based on research and policy/provision mapping and it was informed by consultation with autism stakeholders, including Autistic adults.

> "It may be useful for the [Autism Innovation Strategy] Oversight and Advisory Group to establish what actions from the Programme of Actions on Autism were progressed and which weren't and to seek answers as to why those actions weren't progressed. The background papers such as the mapping and consultation reports can also be made available." (Submission from Statutory Organisation)

7.4 Autism-affirming society

> "[There should be] a campaign that highlights and challenges the stigma that exists in society regarding Autism and disability, so that all services begin to shift from a deficit-focused medical model of disability, to an inclusive social model of disability. The social model underpins the concept of neurodiversity movement. The social model looks at how we can make reasonable adjustments to support neurodivergent people, and it highlights how disabled people are often disabled by barriers in their environment, or people's negative attitudes or exclusions rather than the disability itself." (Submission from Statutory Organisation)

Several suggestions were made as to ways in which society could become more autism-affirming. These included national, local and targeted approaches.

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[24] National Disability Authority (2015) *Children's Disability Services in Ireland*. Available at: https://nda.ie/publications/childrens-disability-services-in-ireland

[25] Health Service Executive (2019) *Transforming Lives: Working Group 1 Report on Future Needs for Disability Services*. Available at: https://www.gov.ie/en/publication/4b75a-transforming-lives-working-group-1-report-on-future-needs-for-disability-services/

[26] Department of Health (2021) *Disability Capacity Review to 2032: A Review of Disability Social Care Demand and Capacity Requirements up to 2032*. Available at: https://www.gov.ie/pdf/154163/?page=1

Whatever the approach, respondents emphasised that it must involve Autistic people at all levels.

Stigma, preconceived notions about autism, and misinformation were all issues respondents raised that needed to be addressed. In addition, there needs to be a move beyond simple awareness-raising and towards an understanding of autism.

Some highlighted the role that the media plays. In this regard, it was suggested that national guidelines and associated training on appropriate language and representation of Autistic people in media and culture should be developed.

Others suggested that national campaigns should also be considered and could, for example, be used in raising awareness of the importance of the environment to support Autistic individuals and in promoting the roll-out of sensory-friendly spaces.

Other suggestions included more targeted Autistic-led awareness-building campaigns with employers, retail outlets, etc. Several submissions highlighted that there is a need to build capacity around autism awareness across many sectors.

7.5 Equality of access to public services

> "I don't want anything showy or flashy, I just want access to [services]…that will help [to make] living more bearable. I want the same access to therapies as non-autistic people have. Services aren't tailored to me and I'm just fobbed off as being too complex and it's really upsetting and disheartening." (Submission from Autistic person)

Most of the suggestions for inclusion in the Autism Innovation Strategy in relation to public services were primarily in the areas of education, employment and health. The following suggestions related to all public services:

> "A human rights approach to the development and delivery of public services is imperative." (Submission from professionals)

> "Cross-departmental working is essential to ensuring the rights of Autistic people are met." (Submission from professionals)

> "Staff working in public services should be given training on how to communicate in an easy way and treat everyone with respect." (Submission from Disability Organisation)

> "Capacity building [should be undertaken] in key departments and agencies on accessible consultation processes with a particular focus on including Autistic people in such consultations. While some may have built up a certain level of

knowledge around making consultation processes accessible to disabled people this could be built upon." (Submission from Statutory Organisation)

Education

In addition to the suggestions on education outlined in Section 6, respondents also proposed the following:

"An expansion of the Occupational Therapy role is advocated to address educational environments, especially the social, physical, and policy aspects, to promote social participation and inclusion." (Submission from professionals)

"Increase Speech and Language and Occupational Therapist supports across the lifespan, and have increased access to therapists within education and employment settings." (Submission from Statutory Organisation)

"Focus more on inclusive education and inclusive practices in mainstream schools and not on the integration models of autistic classes in mainstream education." (Submission from professional)

"[Embed] a universal design approach for learning in education and across health services to make environments more accessible and to reduce barriers." (Submission from Statutory Organisation)

Employment

As well as the suggestions on employment in Section 6, respondents also proposed the following actions:

"[Provide] specialist interview training supports to Autistic people." (Submission from Autism Organisation)

"[Implement] structured mentoring/job-coaching and supports for the person with autism." (Submission from Autism Organisation)

"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." (Submission from Disabled Persons Organisation)

"Extending periods in which Autistic people can retain any supports they use within the Social Protection system, such as the Medical Card [or] Free Travel, when they are in employment to prevent any sudden loss to entitlements if their employment status changes, would be seen [as] a positive step in tackling

> some of the factors that contribute to Autistic individuals and families falling into poverty traps." (Submission from Disabled Persons Organisation)

Health

In addition to the issues already mentioned regarding health services (such as timely access to assessment, early intervention, supports, etc.), a number of specific issues were raised by respondents.

- **Eating disorders and autism**

Some respondents noted that the Autism Innovation Strategy should look at the development of a comprehensive approach to autism and eating disorders. This could be informed, for example, by suggestions from a recent survey of Autistic people, as one submission indicated:[27]

> "Suggested strategies include support for those unable to support themselves[;] support for parents and carers, tailored and designed to a person's needs and circumstances[;] that a person feels listened to and heard[;] experienced and accessible staff[;] good communication from services[;] collaboration between services, education of professionals and practitioners and not using preconceived understandings of Autism." (Submission from professionals)

- **Governance of integrated health and community care systems**

Many respondents saw the inclusion of Autistic people as an important and integral part of processes and structures that impact on their lives:

> "Children and adult services including Progressing Disability Services, Transforming Lives, and Sláintecare should include Autistic people, as per the model of co-design/co-production." (Submission from Disability Organisation)

- **Independent living**

In addition to previous suggestions from respondents about supporting Autistic people to live independently within the community, it was suggested that the Autism Innovation Strategy could pilot and evaluate some of the recommendations made in a report published by the NDA[28] which looked at models of supporting Autistic adults to live fulfilling and independent lives.

- **Local Area Coordination**

There was also a proposal regarding the introduction of Local Area Coordination, and reference was made to previous research which examined how Local Area Coordination worked in other jurisdictions in providing flexible, individualised supports to persons with disabilities:

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[27] Survey undertaken by Bodywhys in partnership with AsIAm in April 2022.

[28] National Disability Authority (2017) *Models of good Practice in Effectively Supporting the Needs of Adults with Autism, without a Concurrent Intellectual Disability, Living in the Community*. Available at: https://nda.ie/uploads/publications/Good-practice-in-supporting-adults-with-autism-2017.pdf

> "The introduction of Local Area Coordination [would] increase community and family support, reduce demand for specialist services, improve access to timely and relevant information and increase supportive relationships within local communities."[29] (Submission from Disability Organisation)

- **Public pathways to diagnosis and support for Autistic adults**

Several respondents raised the issue of having a public pathway to diagnosis and support for Autistic adults:

> "The Autism Innovation Strategy should ensure a public pathway for adult Autism diagnosis and the development of a comprehensive post-diagnosis support, including needs assessment around communication aids, sensory needs, organisational skills, support for community groups, strategies for self-help and neuro-affirmative counselling support." (Submission from Disabled Persons Organisation)

> "It is important that a clear pathway to diagnosis and assessment for Autistic adults when developed is communicated to key health and social care personnel, such as, GPs and mental health professionals." (Submission from Statutory Organisation)

- **Respite**

  Some of the submissions highlighted the increased demand for support services such as respite. One proposal was that the Autism Innovation Strategy could review the model of respite against best practice to see if it is meeting the needs of Autistic children:

> "Autistic people and their families can sometimes feel that they are slotted into services that were developed with a different population in mind, for example, autistic children are placed in respite services which were originally developed for other children with disabilities." (Submission from Statutory Organisation)

7.6 Accessible, inclusive communities

Anti-discrimination

As previously referenced, respondents indicated how awareness-raising leading to a greater understanding of autism plays an important role in enabling Autistic people to engage with and participate in communities. It was also stressed in several of the submissions that tackling discrimination is also very important:

> "Prevailing attitudes towards disability, Neurodiversity, and to neurodevelopmental differences or disabilities like Autism, both within

[29] National Disability Authority (2015) *Local Area Coordination Briefing paper*. Dublin: National Disability Authority. Available at: https://nda.ie/publications/local-area-coordination-nda-briefing-paper

> organisations and across society, can influence whether an Autistic person might feel comfortable or safe to be open about being Autistic in society…[this] can be further compounded if an Autistic person comes from other minority communities and/or has other differences and disabilities." (Submission from Disabled Persons Organisation)

As pointed out in some of the submissions, the prevalence of such attitudes, which can be based on misconceptions and stereotypes, can lead Autistic people to feel that they need to 'mask' or hide parts of themselves that others might feel uncomfortable with in order to fit into society.

Some respondents suggested that the Autism Innovation Strategy presents an opportunity to address issues of anti-discrimination. One example was the following:

> "[Include] Autistic people alongside other cohorts within the community in the process of modernising our anti-discrimination laws, including upcoming hate crime legislation." (Submission from Disabled Persons Organisation)

Affirmative actions

A range of affirmative actions were also suggested for inclusion in the Autism Innovation Strategy, including the following:

> "Support for the roll-out of the [Cara] Centre for Inclusive Sport's Training for Coaches on Understanding Autism." (Submission from Disabled Persons Organisation)

> "Recognition by government of relevant ID cards and self-advocacy supports which enable Autistic people to access support in community settings." (Submission from Disabled Persons Organisation)

> "[Promote] Autistic culture in everyday Irish life through targeted initiatives by the national cultural institutions." (Submission from Disabled Persons Organisation)

> "Review and implement the Ready, Steady, Play: National Play Policy and [promote] the development of inclusive play and leisure spaces as well as recognition of the right to play in the home, community, and school. This can be key for promoting equal access, participation and engagement." (Submission from professionals)

> "Research the issues of Autistic people wanting friends and social opportunities, and explore how this could be facilitated, as this could be of benefit to Autistic people and the wider community in areas like leisure, sports, recreation and the arts." (Submission from Autism Organisation)

Accessible information

The need for accessible information was also raised by respondents with regard to maximising opportunities for Autistic people to participate in all aspects of society. Suggestions included the following:

> "[Ensure] access to Alternative Augmentative Communication." (Submission from Disabled Persons Organisation)
>
> "[Produce] more documents in plain English and easy to read [language] to enable people to participate in all aspects of society. Video resources can be particularly helpful to make things accessible to a wide audience." (Submission from Disability Organisation)
>
> "Reach out to people through different ways: Internet, mail, face-to-face events, including those living in congregated settings." (Submission from Disability Organisation)

7.7 Building capacity and self-advocacy

Several key considerations were highlighted in relation to building capacity, the empowerment of Autistic people, and self-advocacy. These are outlined below.

Access to Augmentative and Alternative Communication

Several respondents were of the view that the Autism Innovation Strategy must embrace and expand the use of Augmentative and Alternative Communication (AAC) and ensure that it is accepted by and accessible to all. Respondents raised the following issues:

> "The prioritisation of verbal communication over non-verbal communication does not align with Article 21 of the UNCRPD which explicitly states that the use of such forms of communication should be facilitated and supported." (Submission from Disabled Persons Organisation)
>
> "This situation is further exacerbated by the lack of support available to those who wish to access AAC, particularly for non-speakers. This includes a lack of expertise and knowledge regarding the different forms of AAC that are available, and a lack of access to these different forms of AAC. There is also a lack of knowledge and training for those who wish to support Autistic people in using AAC." (Submission from Disabled Persons Organisation)
>
> "Most therapeutic interventions offered to Autistic people…place significant emphasis on the use of verbal speech and forms of communication viewed as atypical are discouraged. This denies Autistic people agency and ignores the

> specific importance of non-verbal or non-traditional communication in Autistic culture." (Submission from Disabled Persons Organisation)

Information

A number of respondents made reference to the importance of having accessible information. This empowers Autistic people to make informed choices and to know what services and supports are available to them. A number of suggestions were made, including the following:

> "Adopt a consistent approach to the provision of information to parents/families and adults with autism when a diagnosis is being provided. Develop National Guidance on this and develop a suite of information documents [for] parents/families and people with autism." (Submission from Autism Organisation)

Self-advocacy

Some respondents indicated the need for a self-advocacy service for Autistic people:

> "Families, professionals working with disabled people and the wider community also need to be educated on how to support people with an intellectual disability and autism to make decisions and choices, as opposed to making decisions for them." (Submission from Disability Organisation)

Building capacity for planning services

Respondents highlighted the serious lack of accurate data on the prevalence of autism in the Irish population. Data is critical in the planning of services to support Autistic people. Some of the issues respondents raised in their submissions – for example, around provisions in education for Autistic children – highlighted the need for more accurate data.

Some respondents indicated that the Autism Innovation Strategy provides an opportunity for the development of a national strategy to collect more accurate data on autism prevalence.

It was also suggested that an action around expediting the roll-out of the Children's Disability Network Team Information Management System and linking it with the Health Research Board's (HRB's) National Ability Supports System (NASS) would be important for the Autism Innovation Strategy:

> "Recent changes in the Health Research Board's disability database (replacing the National Physical and Sensory Disability Database and the National Intellectual Disability Database with the NASS means that it now has more potential to capture data on Autism. The planned introduction of a common

> information system (Children's Disability Network Team Information Management System) across all Disability Network Teams, which has the potential to link with the HRB's NASS[,] could contribute significantly to the availability of more comprehensive and timely data on support provision and unmet need for Autistic children." (Submission from Statutory Organisation)

Research

Several respondents made reference to the range of research that has been conducted to date on autism. It was suggested that in order to build on this body of work, the Autism Innovation Strategy should identify key areas of, and provide funding for, further research on autism.

Suggestions for further research included the following:

> "Fund research into prevalence of all types of neurodivergence, the effect of intervention upon children and the economic cost benefit through the lifespan of early access to appropriate therapy." (Submission from parents)
>
> "A focus on supports for autistic individuals who are non-binary or transgender (significant research in this area) is also needed." (Submission from Statutory Organisation)
>
> "Conduct research to capture the experience of autistic people living in Ireland who are experiencing eating disorders. [Ensure that] the research process, from design to completion, includes autistic people." (Submission from professionals)
>
> "Quantify the demand for respite services for Autistic people and the type of respite that best suits their needs." (Submission from Autism Organisation)
>
> "Quantify the demand for Specialist Day Services for school leavers with autism. These should include opportunities to engage in leisure, sports, recreation and the arts." (Submission from Autism Organisation)

8. Conclusion

Central to the respondents' suggestions is that the Autism Innovation Strategy should recognise and uphold the following concepts:

- The Strategy should recognise Autistic people's stated preference for identity-first language.
- Autistic people want to be part of and central to the development, implementation and review of the Autism Innovation Strategy.

- Collaborative engagement must involve reaching out to Autistic people who require AAC. It is important to hear the diverse voices within the Autistic community.
- Co-production and co-design with Autistic people should be part of the Autism Innovation Strategy and delivered both in process (how the Strategy is designed) and in the outputs (ensuring that work is delivered).
- Participation and co-design should also be embedded in the proposed actions of the Autism Innovation Strategy in the areas of research, policy and service provision.
- A clear evaluation plan should be an integral part of the Strategy and the findings of the evaluation should inform future developments and be shared widely with Autistic people in accessible formats.
- The Strategy needs to acknowledge that 'one size does not fit all' and needs to reflect the experience of Autistic people across many different contexts.

With regard to an overarching framework for the Autism Innovation Strategy, key considerations for respondents included:

- The Autism Innovation Strategy should have a human rights framework.
- Several of the submissions highlighted that the Autism Innovation Strategy offers an opportunity to 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 self.
- Proposed actions should be based on the social model of disability.
- It is important to align the Autism Innovation Strategy with other strategies and policies, including the UNCRPD, the National Disability Inclusion Strategy,[30] the Comprehensive Employment Strategy for People with Disabilities, the Disability Capacity Review Action Plan, etc.
- A number of issues raised by respondents had to do with existing services, such as Assessment of Need; early education and care; Progressing Disability Services and inclusive education.
- Consideration will therefore have to be given to aligning the Autism Innovation Strategy with existing strategies across these areas.

Among the key elements respondents suggested for inclusion in the Autism Innovation Strategy are the following:

- The Strategy should identify ways in which society could become more autism-affirming. These included national, local, and targeted approaches. It was stressed that whatever the approach, it must involve Autistic people at all levels.
- The Strategy should address stigma, preconceived notions about autism, misinformation, and the lack of understanding among members of the public in

[30] The National Disability Inclusion Strategy ended in December 2022 but was still in effect when the consultation was carried out.

their attitudes towards Autistic people, as well as within organisations and services that characterise the Autistic identity as being one of 'deficit' rather than 'difference'.

- There needs to be a move beyond simple awareness and towards an understanding of autism.
- The Strategy should include actions to empower Autistic people through such measures as meaningful and early access to AAC, where needed, and through supporting self-advocacy for Autistic people.
- There should be an immediate transition away from damaging behavioural interventionist therapies and towards neuro-affirmative, rights-based supports.
- Public pathways to autism diagnosis for Autistic adults and post-diagnosis supports should be developed.
- A neuro-affirmative framework for education and health services should be developed.
- The Strategy should recognise the importance of Universal Design in addressing barriers to inclusion in the environment.
- The Strategy should address data deficits and promote further research.

There is a consensus from respondents that Autistic people are looking for many of the same things in life as their neurotypical peers – including to be accepted and appreciated for who they are. An underlying expectation is that the Autism Innovation Strategy will begin to change the narrative around autism in Ireland and move towards a neuro-affirmative, person-centred, rights-based approach involving the appreciation of difference.

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