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Analysis of second public consultation on draft Autism Innovation Strategy

August 2024

Contents

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Executive summary

In April 2021, on World Autism Awareness Day, Minister of State with special responsibility for Disability, Anne Rabbitte, announced her intention to develop a new national strategy on autism, the Autism Innovation Strategy.

The Autism Innovation Strategy aims to address the unique challenges and barriers facing autistic people and to improve understanding and accommodation of autism in society and across the public sector. The Autism Innovation Strategy contains actions that will be undertaken across government to better support autistic people and their families over an 18-month period.

The Autism Innovation Strategy will complement and enhance existing and emerging policy by focusing on areas where there are unique challenges or needs for autistic people that are currently unmet within mainstream provision. The goal of the Strategy is to ensure that these needs can be accommodated sustainably as part of mainstream provision and to enhance wider societal understanding and competence in relation to autism.

Consultation with the autistic community has been a central part of developing the Autism Innovation Strategy. This document summarises the feedback received as part of a second public consultation. The purpose of this consultation was to seek the views of autistic people, their families and supporters on the draft Autism Innovation Strategy. The feedback from the public consultation will be used to finalise the Strategy.

The different strands of the second public consultation on the Autism Innovation Strategy took place from January to April 2024. Responses were invited via online survey (EUSurvey), an easy-to-read survey and written submissions between 9 February and 1 March 2024. This report summarises the responses received via the online survey and written submissions.

In addition to the online survey and invitation for written submissions, targeted consultations were held with "seldom-heard" cohorts (i.e. autistic children and non-speaking/minimally speaking autistic people). A meeting was also held with the Autism Innovation Strategy Oversight and Advisory Group, which is majority neurodivergent and composed of a range of people with expert perspectives on autism.

In total, 353 responses were received to the second public consultation via the online survey and written submissions. Of these, 19 responses were from organisations and 334 were from individuals.

Among the 334 individual respondents, 156 (47%) identified as autistic or thought they might be autistic.

Among these 156 respondents, 28 were in the 18–24 years age category; 96 were aged 25–49 years; 22 were 50–64, 2 were 65–79 and 8 preferred not to say.

Executive Summary Table 1: Age breakdown of autistic respondents

Age range	Number of autistic respondents
18-24	28
25-49	96
50-64	22
65-79	2
Prefer not to say	8
Total	156

Regarding gender, 113 (73%) autistic people identified as women, 27 (17%) identified as men, 11 (7%) identified as other and 4 did not answer. Throughout this report, specific attention has been paid to the views of autistic respondents.

A total of 186 people identified as a parent or guardian of an autistic person, of whom approximately one-fifth (44) also identified as autistic.

Of the 186 respondents who identified as a parent or guardian of an autistic person, 131 were in the 25–49 years age category; 47 were aged 50–64, 5 were 65–79 and 3 preferred not to say.

Among the 19 organisational submissions, 12 were from organisations that support autistic individuals, 3 were Disabled Persons Organisations, 2 were statutory bodies, 1 was a health and social care organisation and 1 was a parliamentary group.

As part of the online survey and written submissions, respondents were asked some basic demographic information. They were also asked their opinions on different aspects of the draft Strategy, including:

- The clarity and accessibility of the language used
- The one thing they most liked
- Areas they felt could be improved
- What they considered to be the most important areas for action
- The target audiences and key messages for an acceptance and understanding campaign on autism, and
- Any other comments.

A majority of respondents felt that the language used in the draft Strategy was broadly clear and accessible, the terminology respectful and inclusive, and the structure well organised. Their positive assessment highlighted the avoidance of overly technical language, the good use of headings, and the explanation of terminology and abbreviations. There was strong support for the use of the identity-first term ‘autistic person’ and the neuro-affirmative language used. Several respondents expressed their appreciation for the availability of an easy-to-read version of the draft Strategy. This was acknowledged as a way of improving the document’s accessibility to a wider range of stakeholders.

Respondents, both individuals and organisations, were asked to indicate one thing they liked about the draft Strategy. Analysis of their answers led to the development of four distinct themes~~,~~ which capture what respondents most liked. Three of these are cross-cutting themes: impactful change, rights-focused inclusivity~~,~~ and engagement with autistic people. The fourth theme accommodates the four specific areas for action that were most liked by respondents. These were, in order of priority: health and social care, education, the public acceptance and understanding campaign, and autism training for public services.

All respondents were asked to select three areas for action in the draft Strategy they felt could be improved and then to elaborate the reasons for their choices. The top three areas for improvement identified were:

1. Health and social care (27%)
2. Primary and post-primary education (20%), and
3. Autism training (9%).

Outside of the top three areas for improvement, other areas highlighted (in order of priority) were:

4. Employment (8%)
5. Acceptance and understanding campaign (7%)
6. Early learning and childcare (6%)
7. Parent support (5%), and
8. Access: built environment and design (5%).

Respondents were asked to rank by importance the five areas for action in the draft Strategy which they felt would have the greatest positive impact. For both individual and organisational respondents, health and social care, primary and post-primary education, and autism training featured in their top five priority areas.

The top five for individual respondents also included the acceptance and understanding campaign and employment. The top five for organisational respondents included engagement with autistic people and early learning and childcare.

Executive Summary Table 2: Priority areas under Strategy among individual respondents

Thematic area	Percentage of individual respondents
Health and social care	18%
Primary and post-primary education	13%

Acceptance and understanding campaign	11%
Autism training	10%
Employment	9%

One of the proposed actions in the draft Strategy is to run an awareness and acceptance campaign on autism. Respondents were asked which group from a given list should be targeted in any acceptance and understanding campaign. For individual respondents the breakdown was: the general public 144 (43%), professionals working in an education setting 66 (20%), professionals working in a health and social care setting 58 (18%) and public sector workers 17 (5%).

The submissions from organisations identified a range of target groups. Some organisational and some individual submissions emphasised that an effective national campaign on autism must target a range of audiences and that each target group requires tailored messaging. Two organisations put forward examples of tailored-messaging for specific target groups.

Executive Summary Table 3: Target demographic for an acceptance and understanding campaign on autism

Target Demographic	Percentage of respondents
General Public	43%
Professionals working in an education setting	20%
Professionals working in a health and social care setting	18%
Public sector workers	5%
Other	14%

Analysis of all submissions identified five key messages for any acceptance and understanding campaign, suggesting that it should:

- Challenge misconceptions and stereotypes
- Raise awareness of inclusive practices
- Highlight individual rights and equality
- Emphasise diversity within autism and
- Explain and support neurodiversity

Respondents raised other comments in relation to the draft Strategy. Most of these comments cut across the areas for action. These included:

- Calls for actions which improved co-ordination and collaboration between public services;
- A desire for measurable outputs and details of funding for the Strategy,
- Legislation to reinforce the rights of autistic individuals,
- The representation of autistic women and girls,

- A stronger focus on autistic adults, and the rejection of behavioural interventions.

Several respondents also highlighted other areas they felt should be included in the Strategy, such as housing and supported living, safeguarding and political participation.

Context

The *Programme for Government: Our Shared Future* contains a commitment to action on autism. In April 2021, on World Autism Awareness Day, Minister of State with special responsibility for Disability, Anne Rabbitte, announced her intention to develop a new national strategy on autism, the Autism Innovation Strategy, in furtherance of this commitment.

The Autism Innovation Strategy aims to address the unique challenges and barriers facing autistic people and to improve understanding and accommodation of autism in society and across the public sector. The Autism Innovation Strategy contains actions that will be undertaken across government to better support autistic people and their families over an 18-month period.

The Autism Innovation Strategy will complement and enhance existing and emerging policy by focusing on areas where there are unique challenges or needs for autistic people that are currently unmet within mainstream provision. The goal of the Strategy is to ensure that these needs can be accommodated sustainably as part of mainstream provision and to enhance wider societal understanding and competence in relation to autism.

The Autism Innovation Strategy will complement and enhance wider reform efforts by focusing on areas where there are unique challenges or needs for autistic people. For example, the *Action Plan for Disability Services 2024–2026* is at the centre of renewed strategic reform efforts to deliver tangible service improvements for all people supported by disability services, including autistic people.

Similarly, in the context of children's disability services, the *Roadmap for Service Improvement 2023-2026* seeks to address the significant challenges faced by Children's Disability Network Teams (CDNTs), including waiting lists, staffing vacancies and the growing demand for services and Assessments of Need.

A new National Disability Strategy is also being developed to provide a blueprint, developed in partnership with disabled people including autistic people and their representative groups, for continued implementation of the United Nations Convention on the Rights of Persons with Disabilities in Ireland and to further support the rights and inclusion of all disabled people.

Similarly, and in line with Ireland's commitment to the United Nations Convention on the Rights of Persons with Disabilities, autistic people and their families, friends, co-workers, representatives and support networks have been involved in the development of the Autism Innovation Strategy from the outset.

An initial public consultation to inform the design and development of the Strategy was held between April and May 2022. Fifty-one comprehensive submissions were received, including several from umbrella organisations that collated a large number of responses from their members. A report analysing the submissions was published in April 2023. The key findings identified in the report were critical in informing the initial draft of the Autism Innovation Strategy.

The second phase of the development process, an application process for membership of the Autism Innovation Strategy Oversight and Advisory Group, was launched in June 2022. The group was appointed in December 2022 and met most recently in January 2024. The group is majority neurodivergent and includes autistic people, professionals, parents and organisations. The group will play a key role in monitoring implementation of the Strategy once adopted and in providing advice to guide whole-of-government work on autism.

Following publication of the first consultation report and appointment of the Autism Innovation Strategy Oversight and Advisory Group, work began on drafting the Strategy. Extensive bilateral engagements were held with relevant Government Departments and statutory agencies to identify actions to respond to the issues raised in the public consultation. During this process, detailed consideration was also given to the recommendations of the Joint Oireachtas Committee on Autism. The draft Autism Innovation Strategy was published in February 2024, along with an easy-to-read version of the draft Strategy.

A consultation process was commenced to give the autistic community and their supporters a further opportunity to have their say on the Strategy before its finalisation and launch.

The consultation process had various strands. Written submissions, online survey responses and easy-to-read survey responses were invited from 9 February to 1 March 2024. In addition, targeted consultations were held with cohorts that were identified as "seldom heard" during the first consultation. Individual and group interviews, both in person and online, were held with autistic children and young people and non-speaking and minimally speaking autistic people. Reports from these targeted consultations are being published separately. A meeting of the Autism Innovation Strategy Oversight and Advisory Group was also held to discuss the draft Strategy.

This consultation report summarises the feedback received via the online survey (EUSurvey) and written submissions. As part of the consultation, respondents were asked for their opinions on different aspects of the draft Strategy, including:

- The clarity and accessibility of the language used
- The one thing they most liked
- Areas they felt could be improved
- What they considered to be the most important areas for action
- The target audiences and key messages for an acceptance and understanding campaign on autism, and

- Any other comments.

Responses were invited from anyone with an interest in commenting on the draft Strategy. In particular, submissions were welcomed from autistic people and their families, friends, representatives and key supporters.

About respondents

The second public consultation on the draft Strategy generated a total of 353 responses. Of these, 19 were from organisations and 334 from individuals. Organisations were differentiated by type. Individual respondents were asked to provide some basic demographic information about their autism status, age category (if identifying as an autistic person or as a parent or guardian or an autistic person), group identification, gender (if autistic) and the type of area in which they live.

Autism status

Among the 334 individual respondents, 156 (47%) identified as an autistic person or thought they might be an autistic person, 148 (44%) identified as an allistic/non-autistic person, 25 (7.5%) did not know, and 5 (1.5%) preferred not to say.

Table 1: Identification of individual respondents

Identification of respondents	Number of respondents
Autistic	156
Allistic/non-autistic	148
I don’t know	25
Prefer not to say	5
Total	334

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Age

Of the 334 individual respondents, those that identified as an autistic person~~,~~ or as a parent or guardian of an autistic person~~,~~ were asked to specify their age category.

Among the 156 respondents that identified as an autistic person, 28 were aged 18–24 years, 96 were aged 25–49, 22 were 50–64, 2 were 65–79, and 8 preferred not to say. No respondents who identified as an autistic person were in the 80+ years age category.

Among the 186 respondents who identified as a parent or guardian of an autistic person, 131 were aged 25–49 years, 47 were aged 50–64, 5 were 65–79, and 3 preferred not to say. No respondents who identified as parents or guardians of an autistic person were in the 18–24 or 80+ age categories.

Table 2: Age breakdown of autistic respondents

Age bracket (years old)	Number of autistic respondents

18-24	28
25-49	96
50-64	22
65-79	2
Prefer not to say	8

Table 3: Age breakdown of parents/guardians

Age bracket (years old)	Number of parents/guardians
18-24	0
25-49	131
50-64	47
65-79	5
Prefer not to say	3
Total	186

Gender

Among the 156 autistic individual respondents, the gender breakdown was as follows: 113 (73%) identified as women, 28 (17%) identified as men~~;~~, 11 (7%) identified as other~~;~~, and 4 (3%) preferred not to say.

Table 4: Gender of autistic respondents

Gender	Number of autistic respondents
Female	113
Male	28
Other	11
Did not answer	4
Total	156

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Location

Of the 334 individual respondents, 331 answered the question on the type of area where they lived: 158 (48%) lived in a city or large town, 113 (34%) lived in a small town or village, and 60 (18%) lived in the rural countryside.

Group representation

The 334 individual respondents were asked to indicate which of a number of groups best represented them. Respondents could select more than one group to capture their multiple identities. This means that the following figures add up to the total number of boxes selected (511) rather than the total number of individual respondents:

- 156 (47%) "I am autistic"
- 186 (56%) "I am the parent or guardian of an autistic person"; of whom 44 (24%) also identified as autistic
- 48 (14%) "I am a close family member of an autistic person"
- 38 (11%) "I am the carer of an autistic person"
- 36 (11%) "I am an education professional"
- 26 (8%) "I am a health and social care professional"
- 18 (5%) "Other", and
- 3 (1%) "I am supporting an autistic person to complete this survey".

Of the 156 individual respondents who identified as an autistic person, 44 (28%) identified as a parent or guardian of an autistic person, 27 (17%) identified as a close family member of an autistic person, 15 (10%) identified as a carer of an autistic person, 9 (6%) identified as an education professional, and 8 (5%) identified as a health and social care professional.

Organisations

Of the 19 organisational respondents, 12 were organisations that support autistic individuals, including not-for-profit organisations, voluntary organisations, umbrella organisations and organisations that provide services to autistic people; 3 were Disabled Persons Organisations; 2 were statutory bodies; 1 was a health and social care organisation; and 1 was a parliamentary group. Many of these organisations referred to wider consultation with their membership groups in informing their submission responses.

Table 5: Breakdown of organisational submissions

Category of organisation	Number of submissions
Organisation that supports autistic people	12
Disabled persons organisation	3
Statutory body	2
Health and social care organisation	1
Parliamentary group	1
Total	19

Language

Respondents were asked to assess the clarity and accessibility of the language used in the draft Autism Innovation Strategy. Most respondents felt that the language used in the draft Strategy was clear and accessible, the terminology respectful and inclusive, and the structure well organised. Their positive assessment highlighted the avoidance of overly technical language, the good use of headings, and the explanation of terminology and abbreviations. There was strong support for the use of the identity-first term 'autistic person' and the neuro-affirmative language used in the Strategy. Several respondents expressed their appreciation for the availability of an easy-to-read version of the draft Strategy. This was acknowledged as a way of improving the document's accessibility to a wider range of stakeholders.

Of the 324 people who answered this question on language, over 90% of respondents answered either "Yes" or "Partly" to the question: "Do you feel that the language used in the draft Autism Innovation Strategy is clear and accessible?". The breakdown of responses was: "Yes"180 (56%), "Partly" 120 (37%) and "No" 24 (7%). When asked to elaborate on the language used, several individuals who had either answered "No" or had not answered the earlier question were strikingly positive. This suggests that the analysis of the quantitative data slightly underestimates how positive respondents felt about the clarity and accessibility of the language in the draft Strategy.

Of the 324 people who answered this question on language, 140 identified as autistic. Among autistic respondents, over 90% answered either "Yes" (49%) or "Partly" (42%) to the question, while 13 (9%) responded "No". Similar, too, is the overall positive response from the 16 organisational submissions that answered this question: 9 "Yes", 6 "Partly" and 1 "No".

Table 6: *Breakdown of responses to question: Do you feel that the language used in the draft Autism Innovation Strategy is clear and accessible?*

Respondent type	Yes	Partly	No
All individual respondents	180	120	24
Autistic respondents	68	59	13
Organisations	9	6	1

Accessibility of language

A majority of respondents felt the language used in the draft Strategy was relatively clear and accessible. Their broadly positive assessment highlighted the avoidance of overly technical language, the good use of headings, and the explanation of terminology and abbreviations:

> "It's very clear and easy for me to read, the language used isn't too complicated." (autistic person)

> "I had no difficulties in reading the paper. The language used is clear and concise, abbreviations are explained. There are no complicated words used." (parent/guardian of an autistic person)

> "From our reading of the draft Strategy, we feel the language used is clear and accessible. The terminology is respectful and inclusive, avoiding overly technical terms or abbreviations. The concepts within each of the key pillars are explained in a straightforward manner making it easy for a broad audience to understand." (Health and social care organisation)

Some respondents felt that the language used in the draft Strategy was too complex, however, and would benefit from the use of plain English to make it more accessible. It was also suggested that there was scope for the use of bullet points to simplify sentences, especially those used to describe the proposed actions:

> "Creideann [ár n-eagraíocht] go bhfuil an leibhéal teanga sa straitéis ag leibhéal ró-ard don ghnáthléitheoir." (organisation that supports autistic people; original in Irish)

> "[Our organisation] believes that the level of language in the strategy is too high for the ordinary reader." (organisation that supports autistic people; translated from original in Irish)

> "A plain English service could help make the wording more accessible. The use of summaries, bullet points and images before large sections of text are also helpful for all audiences not just [neurodivergent people]." (autistic person)

> "Potentially break the aims of the innovation strategy into more concise bullet points…for those who find reading difficult or [have] focus difficulties, include accommodating visuals to aim understanding." (autistic person)

Terminology

Most respondents found the terminology used in the draft Strategy respectful and inclusive. There was strong support for the use of the identity-first term 'autistic person' and neuro-affirmative language:

> "I'm mostly really impressed. Clear, inclusive, thoughtful language." (Disabled Persons Organisation)

> "Yes, the language is clear. I am pleased to see that real attempts have been made to use neuro-affirming language throughout." (parent or guardian of autistic person; close family member of autistic person)

> "We also believe that the use of identity-first language throughout the draft Strategy reflects that many Autistic people see being Autistic as a core and central part of their identity, and to their experience living in Irish society." (Disabled Persons Organisation)

Analysis of the 334 submissions from individual respondents found that 42 people (13%) capitalised the terms 'Autism' and 'Autistic'. Of these 42 people, 17 identified as an autistic person, 5 did not know, and 20 identified as allistic/non-autistic. Among the 19

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Commented [dcediy6R5]: Timothy to check please organisational submissions, 3 (15%) organisations capitalised ‘Autism’ and ‘Autistic’. No reference was made in respondents’ submissions to the non-capitalisation of these terms in the text of the draft Strategy. Although the majority of respondents were explicit in their support for the term ‘autistic person’, it was acknowledged that terminology evolves and its use remains contested:

> “[A] major point of feedback stemming from our work supporting young people is that, increasingly, many autistic people prefer to use the terminology ‘neurodiversity’/‘neurodivergent’ rather than ‘autism’/‘autistic’, for several reasons: first, that autism/ASD [autism spectrum disorder] is seen as pathologising and, to some, stigmatising; and that due to long waiting lists and the prohibitive costs of going private, many people struggle to obtain an official diagnosis of autism for a long time. As such, neurodiversity is often embraced as a broader and more inclusive term, which also recognises the diversity within this community and the intersectionality of many neurodivergent conditions including autism, ADHD [attention deficit hyperactivity disorder], dyslexia, dyspraxia, etc.” (organisation that supports autistic people)

Respondents commented on the use of various specific terms. It was felt that some terms:

- Needed explanation (e.g. ‘neuro-affirmative’, ‘neurodivergent’, ‘autism friendly’ and ‘fully inclusive’)
- Needed explanation earlier in the document text (e.g. ‘JAM card’), and
- Were not in keeping with the neuro-affirmative ethos of the document (e.g. ‘condition’, ‘diagnosis’ and ‘non-speaking’).

Some concerns were raised about the absence of specific terms from the document and that this warranted explanation (e.g. ‘spectrum’, ‘Asperger’s’ and ‘ASD’). Other concerns noted that the language used in the draft Strategy did not reflect the varying levels of need among autistic people:

> “Whilst I agree with removing the labels high functioning and low functioning, I don’t agree with removing the levels and using an all-inclusive language. I believe this homogenises autistic children/adults. These levels are generally used and helpful in clinical settings because whether we like it or not clinical settings are part of the journey.” (parent/guardian of an autistic person)
>
> {C]urrent language is outdated and not reflective of the needs of autistic people. Primary focus seems to be for those with higher observable support needs and does not take in to consideration that a lot of autistics internalise difficulties and appear to have low support needs.” (statutory body)

It was suggested the document would benefit from the inclusion of a glossary:

> "The Strategy could be improved by adding a glossary of common terminology, including such terms as 'stimming', 'masking', 'neurotypical', 'ASD' etc." (organisation that supports autistic people)

Structure

A majority of respondents felt that the draft Strategy was clearly laid out in terms of its structure and use of sub-headings:

> "It is broken down into paragraphs into chapters and into bullet points. That certainly helps me as an autistic [person] to understand the draft policy." (autistic person; close family member of an autistic person).

> "Sections and headings helped to sort topics and facilitate the scanning of the document and a quick decision to be made as to which elements of the document to concentrate on." (autistic person; parent or guardian of an autistic person; education professional)

> "It is clear, concise and user friendly. It is a well-structured document." (education professional)

Respondents made several suggestions about how the structure of the draft Strategy could be improved. These included:

- Visual signposting
- More defined paragraphs and headings
- Less/no referencing other documents in the main text
- More user guidance about the purpose of the sections
- Better explanations of the data tables, and
- A review of the numbering system and/or structure of the "Actions Table".

Other accessibility considerations

Several respondents expressed their appreciation for the availability of the easy-to-read version of the draft Strategy. This was acknowledged as a way of improving the document's accessibility to a wider range of stakeholders. An easy-to-read version of the survey questions was also published. There were some concerns, however, that the easy-to-read version of the draft Strategy did not provide enough detail:

> "I really appreciated the easy to read version. It really suits me to read a high-level over view before I read a more complex document or even just look at the sections of the long version that I wanted more information on." (autistic person)

> "We have also noted that an easy to read version of the draft Strategy is available. This too is important because it ensures accessibility for a wider audience, including individuals with varying levels of literacy, cognitive abilities and neurodiversity." (health and social care organisation)

> "The easy to read version was used by our members however we had to refer back to the main document continuously as there is a lot more detail there. Easy to read should be, in so far as possible, detailed, informative AND accessible." (organisation that supports autistic people)

Some respondents expressed a desire for the draft Strategy and its public consultation to be made available in different formats, namely Irish language, video explainers, audio versions and versions for those using Augmentative and Alternative Communication (AAC).

One thing liked

Respondents, both individuals and organisations, were asked to indicate one thing they liked about the draft Autism Innovation Strategy. Analysis of their answers led to the development of four distinct themes which capture what respondents most liked. Three of these are cross-cutting themes: impactful change, rights-focused inclusivity and engagement with autistic people. The fourth theme accommodates the four specific areas for action most liked by respondents.

These were, in order of priority: health and social care, education, acceptance and understanding campaign, and autism training for public services. Comparisons were also made of differences in what was most liked between autistic and other individual respondents, and between parents and guardians of autistic persons and all other individual respondents. The analysis of what respondents liked about the draft Strategy is presented below.

Impactful change

Many respondents liked aspects of the draft Strategy which fall under the theme of "impactful change". Respondents appreciated the Strategy's comprehensiveness in covering a broad range of areas for action relevant to the everyday lives of autistic people. Also, that specific actions were linked to the Government Departments, statutory agencies and bodies responsible for their delivery. This theme encompassed respondents' appreciation of the draft Strategy's ambition~~,~~ as well as the significance of its publication:

> "The Autism Innovation Strategy in Ireland reflects growing societal awareness of autism [and] represents gradual progress towards acknowledging autistic individuals' specific needs. Its mere existence suggests that the work of advocacy groups has paid dividends." (autistic person)
>
> "As an organisation working with families and supporting parents, we are delighted to see that the Government is striving to consult and research what actions are needed to make a difference to the lives of autistic people in Ireland. The timeframe of 18 months set out for delivering the actions along with a vision for the Strategy to serve as a platform of building blocks for [a] more autism-inclusive society brings the focus and marks the importance of change." (organisation that supports autistic people)
>
> "Your efforts have the potential to make a significant difference in the lives of autistic people and their families. By developing innovative strategies tailored to their needs,

> you’re actively working towards creating a more inclusive and supportive society.” (statutory body)

Rights-focused inclusivity

Respondents welcomed the emphasis on rights-based approaches in the draft Strategy. They liked the inclusive, rights-focused and neuro-affirming ethos of the four pillars which underpin its proposed actions. Respondents also liked the inclusiveness of the neuro-affirmative language used, as already highlighted in the “Language” section:

> “The commitment to advance human rights and inclusion of autistic people, it is personally very important as I feel excluded from the rest of society.” (autistic person; close family member of an autistic person)

> “I liked the commitment to the neuro-affirmative approach, and the use of identity first language.” (autistic person; parent/guardian of an autistic person)

> “We welcome that the draft Strategy is rights focused, and is underpinned by the fundamental principles of the UNCRPD…alongside the Strategy’s values of being neuro-affirmative and focused on delivery within the mainstream – if achieved, this has the potential to be empowering to autistic people.” (organisation that supports autistic people)

Engagement with autistic people

Many respondents expressed satisfaction with the involvement of autistic individuals in the development of the draft Autism Innovation Strategy and the identification of engagement with autistic people as an area for action in the document itself. Autistic respondents had a stronger liking for the theme “engagement with autistic people” than allistic/non-autistic respondents:

> “It very clearly had been written in consultation with actually autistic people. I felt represented.” (autistic person)

> -“In order to truly be an autism strategy, we must be informing any plans or actions with a majority input coming from autistic people and being valued as such. The reason things have historically been so bad is because the decision makers over the decades have been people who have not got the lived experience required to make the decisions.” (autistic person; parent/guardian of an autistic person).

> “The points were informed and well thought out, clearly as a result of the meetings with the [Autism Innovation Strategy Oversight and] Advisory Group. I am very pleased to see that autistic people are being involved in this Strategy.” (autistic person)

> “We liked the efforts made to ensure accessibility of autistic people to the consultation process. Strategies must be developed in consultation with the people who are most impacted by it and the draft Autism Innovation Strategy is no different.” (health and social care organisation)

Specific areas for action

In responding to this question, respondents also highlighted specific areas for action they liked. The four most-liked areas for action were, in order of priority: health and social care, education: primary and post-primary, the acceptance and understanding campaign, and autism training. These are detailed below.

Health and social care

Many respondents liked health and social care as an area for action in the draft Strategy. Particularly liked were actions related to improving access to mental health support for autistic children and adults; the acknowledgement of co-occurring conditions often experienced by autistic individuals; and the proposed public pathway to diagnosis and support for autistic adults:

> “The wide scope of recommendations especially regarding mental health needs of autistic people through the lifespan. Autistic people are more at risk than non-autistic people to be left in limbo when services won’t agree who should take the lead in their care. This is not acceptable. Improved processes for shared care need to be realised. The commitment to tangible action and commitment to review of progress is positive.” (health and social care professional)

> “I very much like that there is an aim to have a public pathway to diagnosis and support for Autistic adults, as currently the system is a misery.… ~~—~~ …My only option currently is to go private and that is not financially possible for me, so it is heartening to see that a public pathway is on the agenda.” (autistic person; parent/guardian of an autistic person)

> “~~“~~One thing we liked about the strategy was the acknowledgment of the fact that many autistic people experience co-occurring conditions. What was mentioned was correct, but not expansive enough. We would like to draw attention to the fact that many autistic people also experience medical conditions such as Ehlers Danlos Syndrome and many autoimmune conditions. The more common conditions that may co-occur in autistic people include attention deficit hyperactivity disorder.” (Disabled Persons Organisation)

Education: Primary and post-primary

Many respondents indicated they liked the areas for action ~~within~~ in the draft Strategy that cover education:

> “Tá an t-aitheantas atá tugtha do thábhacht an oideachais mar bhunphrionsabal ag croílár an [na straitéise] ó leibhéal na luathbhlianta agus cúram leanaí suas trí na leibhéil ríthábhachtach….Cuireann muid fáilte mhór roimh na tacaíochtaí breise atá luaite faoin oideachas.” (organisation that supports autistic people; original in Irish)

> “The acknowledgement of the importance of education as a basic principle at the heart of the [Strategy] from early years and childcare up through the different levels is vital….We welcome the extra supports that are mentioned under education” (organisation that supports autistic people; translated from original in Irish)

> "In general, a focus on the quality of the education experience for Autistic students is welcome. This is sorely lacking in the current system.….We should be able to demand the highest quality education experience for all children. It is not just about adding more resources to the system it is about reviewing, monitoring and improving children's experiences." (organisation that supports autistic people)

Acceptance and understanding campaign

Respondents liked the proposed autism acceptance and understanding campaign:

> "I welcome the introduction of an awareness campaign as part of pillar 1. Before my son was diagnosed, I had a very narrow view of autism and I think it's great that in addition to society becoming more accommodating through other actions in the strategy that there's a general societal education piece around autism."
> (parent/guardian of an autistic person)

> "For mainstream engagement to be fully possible for autistic people, the development of wider understanding, acceptance, and accommodation of their needs is a necessary prerequisite". (organisation that supports autistic people)

Autism training

The focus in the draft Strategy on providing autism training to staff working across various public services (such as health and social care and education) was welcomed by respondents. It was seen as addressing an identified and important barrier to accessing public services for autistic individuals:

> "The provision of autism training to employees in the public service, particularly the HSE [Health Service Executive] and educational institutions" (autistic person)

> "I also like that it recognises the need for more training and that being Autism Aware is simply not enough." (parent/guardian of an autistic person; health and social care professional)

> "The draft Autism Innovation Strategy contains some welcome measures, particularly in the areas of providing training and guidance to staff working across a range of public services on best practices in Autism Acceptance and Understanding, and around making public services more accessible to our community. These include rolling out training aimed at increasing Autism understanding and acceptance across the public sector, focusing on bespoke training for professionals and staff who are working in health and social care, in mental health services, and in the education sector." (Disabled Persons Organisation)

Group preferences

Deeper analysis of what respondents liked about the draft Strategy revealed subtle differences in preferences between autistic and allistic/non-autistic respondents, and between parents and guardians of autistic persons and all other respondents. The analysis of what these groups of people liked about the draft Strategy is presented below.

Comparison was made between what autistic individual respondents as a group most liked about the draft Strategy and what individual allistic/non-autistic respondents as a group most liked. Analysis showed that both groups' most-liked cross-cutting theme was "impactful change". Autistic respondents, however, had a stronger liking for the theme "engagement with autistic people" than allistic/non-autistic respondents.

Comparison was made between what parents and guardians of autistic people liked about the draft Strategy and all other individual respondents. The most-liked cross-cutting theme among parents and guardians of autistic people was "impactful change", whereas for all other individual respondents the most-liked cross-cutting theme was "rights-focused inclusivity".

Areas for improvement

Respondents, both individuals and organisations, were asked to select three actions in the draft Autism Innovation Strategy they felt could be improved and then to elaborate on their choice. The top three areas for improvement identified were: health and social care (27%), primary and post-primary education (20%) and autism training (9%).

Outside of the top three areas for improvement, other areas highlighted (in order of priority) were:

- Employment (8%)
- Acceptance and understanding campaign (7%)
- Early learning and childcare (6%)
- Parent support (5%), and
- Access: built environment and design (5%).

The key recommendations for change under each of the top three areas for improvement are summarised by theme below.

Health and social care

Respondents' feedback highlighted a number of areas which they felt could be improved under the proposed actions for health and social care. These included access to identification/assessment services, autism training, child and adolescent mental health services, and adult mental health services.

Access to assessment

Many respondents called for a national roll-out of a public pathway to assessment of autism, with state funding for private identification services until a public pathway is established:

> "Most of us have to pay for our assessments out of pocket or wait years as so few clinicians are available to assess autistic adults." (autistic person)
>
> "As someone who was undiagnosed my entire life and only found out about my autism a few years ago, I was told to wait and wait for some sort of assessment through the HSE [Health Service Executive] and then later [was] told there were none for adults. I was told private was the only way, which is very costly. I did get a private diagnosis eventually but

> was failed by the HSE [Health Service Executive] in this." (autistic person; parent/guardian of an autistic person)
>
> "This is an inadequate level of commitment to identification services given that many adults may lack access to services when they really need them due to a lack of financial access to private identification services. We need a national roll-out of a public pathway to identification, and the state should pay for private services while we await public ones." (Disabled Persons Organisation)

Autism training

Although autism training for health and social care professionals is mentioned under the draft Strategy, many respondents called for its inclusion under the area of health and social care. Respondents emphasised that autism training should be mandatory for all health and social care professionals and cover common co-occurring conditions:

> "Ensuring individuals, especially women and other 'non-stereotypical' presenting people get proper diagnosis and are accepted is important in reducing suffering and allowing them to seek support if they need it. Healthcare can be an especially challenging area for autistic people due to differences in communication, ability to monitor bodily sensations and traumatic experiences. This is even more true as many autistic people have comorbid health and mental health conditions. Healthcare workers need to be given more information and training to help them when dealing with autistic people in order to improve outcomes and reduce suffering." (autistic person)
>
> "We all have had issues with healthcare professionals not understanding autism. There should be a mandatory training programme for all healthcare professionals to do." (parent/guardian of an autistic person; carer of an autistic person)

Child and adolescent mental health services

Many respondents noted the absence of an action to expand the capacity and resources for child and adolescent mental health services. They also highlighted the lack of mention of multidisciplinary teams to address co-occurring mental health conditions, which would improve access to services through better co-ordination:

> "How can our main child and adolescent mental health services (CAMHS), not be able to diagnose or work with autistic children and adolescents? How can our CDNT [Children Disability Network Teams] claim autism is not a disability and therefore fail to see our young person, when they have so [many] needs. How can an autistic person fall between care services?" (autistic person; parent/guardian of an autistic person; carer of an autistic person; close family member of an autistic person)
>
> "I don't see any mention of adding capacity/resources to CAMHS to allow for the timely treatment of autistic kids with mental illness, or the common intersectionality of [autism and] ADHD." (parent/guardian of an autistic person; close family member of an autistic person)

> "The abolition of [multidisciplinary] early intervention teams within primary care has led to disjointed services for young autistic children and much delayed access to [occupational therapy] & psychology services. Reversal of this decision would have a greater impact on future mental health than a pathway finder. (parent/guardian of an autistic person; close family member of an autistic person; health and social care professional)

> "An enhanced model and practice for autistic children with co-morbid significant mental health presentations was recommended in feedback to our consultation. Some member organisations have pointed to the presence of autism, resulting in network disability teams being designated as the primary service provider for a child even where mental health needs may be having the most significant functional impact for the child. This has resulted in some individuals not being able to access the mental health services that their mental health needs would indicate. There is therefore a need for enhanced collaborative approaches to ensure that children can access all of the services that they require, regardless of the division or department responsible for delivery." (organisation that supports autistic people)

Adult mental health services

Aside from the provision of mental health services for adults with substance use problems and suicide prevention support, several respondents highlighted the lack of a proposed action for mental health services for autistic adults:

> "There has to be free, high-quality, accessible and culturally competent mental health support across the board, particularly for autistic people. This action cannot be restricted to crisis situations like suicide prevention - when I was an autistic teenager I was not able to get help until I was acutely suicidal, and then I got counselling from a charity. To note, suicide prevention should be mentioned as this is a big issue in the autistic community but so should gender-affirming healthcare and eating disorder treatment, where there is also significant overlap." (autistic person)

> "Mental health supports for autistic people are virtually non-existent." (organisation that supports autistic people)

> "Those with substance issues and those who have suicidal feelings, as well as children and teens…should all receive mental health assistance, autistic or not. But there is also a significant proportion of the autistic population (likely the majority I'm guessing from a demographic perspective) who are adults [who] don't fall into one of these categories, [and] who experience significant challenges emotionally and mentally, by being autistic in this world, who receive virtually no assistance, even in this [Strategy]. I received free therapy appointments during covid that were such a life saver. Perhaps either making… public therapy appointments available to autistic people, or providing funding to private services." (autistic person)

Primary and post-primary education

Many respondents called for improvements to the proposed actions under the area of primary and post-primary education. The most common themes were: autism training, inclusive schooling, support for transition years and work experience, and assistive technology:

Autism training in education settings

Respondents called for autism training in education settings to be rights-based, neuro-affirmative and compulsory for teachers and special needs assistants (SNAs):

> “Training in autism should be mandatory for all teachers and education staff, not optional, not only for resource teachers or autism class teachers.” (autistic person; parent/guardian of an autistic person; health and social care professional)

> “Develop a training programme on Autism which is available to all teachers at all stages of their training and career, in primary and post-primary schools, based on neuro-affirmative practices on supporting people at school and in line with best practices set out by Article 24 and General Comment 4 of the United Nations Convention on the Rights of Persons with Disabilities.” (Disabled Persons Organisation)

> “Every teacher should be trained in the autism good practice guidelines as things have changed dramatically in the last 10–20 years. Regular CPD [continuing professional development] should be mandatory to make sure educational staff are well versed in autism needs and supports. SNAs should also receive the same training as they are working closely with these students every day.” (education professional)

Inclusive schooling

Respondents made a number of suggestions around making schooling more inclusive for autistic students. These included reviewing school codes of behaviour, creating sensory spaces and making the built environment of schools more accessible, and tailoring Relationship and Sexuality Education to the needs of autistic students:

> “Sanction the creation of sensory spaces and gardens in all new schools. Allocate specific funding under the Minor Works Scheme for all schools to put in place appropriate sensory spaces, based on best practices.…Review building guidelines for schools against the ASPECTSS framework [acoustics, spatial sequencing, escape space, compartmentalisation, transitions, sensory zoning, and safety] and best practices around Universal Design to make school environments, such as classrooms, school halls, corridors and facilities, more accessible to Autistic pupils.” (Disabled Persons Organisation)

> “Recommendation [6.1] could be strengthened further. To ensure that all students, including autistic students, can learn in a safe and supportive environment.…Ensure that the guidelines are children’s rights focused.…Provide training for schools on the new guidelines which is trauma-informed, relationship-focused and neuro-affirmative.” (organisation that supports autistic people)

> "Ensure that the roll-out of the revised Relationships and Sexuality [Education] curriculum, and the relevant support materials, including information around consent, and around reproductive and sexual health, are accessible for Autistic people." (Disabled Persons Organisation)

Support for school transition years and work experience

Commented [dcediy7]: Headings to change please

Respondents recommended the inclusion of actions to support school transition years and work experience for autistic students:

"Recognising the high levels of Autism unemployment, explore how opportunities can be developed to support work experience opportunities and initiatives for Autistic secondary school students. Additionally, develop guidelines to improve the accessibility of the Transition Year programme to support Autistic students, and support schools to act on its recommendations." (Disabled Persons Organisation)

Assistive technology in schools

Respondents wanted actions to include improved access to assistive technology funding for autistic students and follow-up support in schools:

> "The lack of support around assistive technology is another huge issue with regard accessing the curriculum. Personally, after a full academic year of waiting for funding, we purchased our son's assistive technology. The second issue is the lack of information/support regarding programmes to use for assistive technology." (parent/guardian of an autistic person; carer of an autistic person)

> "The assistive technology grant is hard to access and not followed up well in schools. In addition…ipads/laptops etc. only have a lifespan of four years maximum, but the system does not acknowledge this at all." (organisation that supports autistic people)

Autism training in the context of education

Respondents made several suggestions about how to improve the draft Strategy's proposed actions regarding autism training. These included the neuro-affirmative framing of any training, involving autistic people in training design and delivery, strengthening public service training, and the expansion of training across various sectors.

Neuro-affirmative training

Several respondents called for all training actions to be framed within a neuro-affirming theory of practice in line with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD):

> "The *Autism Good Practice Guidance for Schools* includes reference that ABA [Applied Behaviour Analysis] and PBS [Positive Behaviour Support] 'may be helpful in complementing other effective teaching practices'. [We] strongly oppose the use of such compliance-based behavioural interventions, which the Disability Matters Committee found…'cannot uphold the UNCRPD principles of autonomy, dignity, right to identity and freedom from non-consensual or degrading treatment.' Neurodiversity

> affirming supports already exist, and these should be promoted by the government instead.” (Disabled Persons Organisation)

Involvement of autistic people

Respondents recommended that the design and delivery of autism training should be centred around the lived experience of autistic people, involve relevant stakeholder organisations, and consider accommodations for autistic trainers and participants:

> “Autistic people (as well as Autism specialists) need to be at the centre of designing and delivering training. They are best placed to educate people on what it is like to be autistic. There is no substitute for lived experience…” (organisation that supports autistic people)

> “Consultation and direct engagement with NGOs [non-governmental organisations]…working with autistic people will be vital to the development and delivery of this work, and resourcing will be required.” (organisation that supports autistic people).

Strengthening public service training

Respondents recommended a number of measures to strengthen autism training aimed at public service professionals. These included a review of continuing professional development (CPD) requirements, comprehensive training for educators, and mandatory training for Health Service Executive staff:

> “Building on the recommendation to roll out Autism Understanding and Acceptance training across the public sector, review the CPD requirements around Autism for relevant professionals and make Autism Understanding and Acceptance training available that is relevant to their profession or industry.” (Disabled Persons Organisation)

Expansion of training across various sectors

Respondents called for the expansion of autism training across various sectors. These included youth worker staff and volunteers to support inclusive spaces for autistic young people; dieticians due to the co-occurrence of autism and eating disorders; Tusla – Child and Family Agency staff; local authority staff, particularly within the homeless service; the ambulance service; court judges; and police workers.

Other areas for improvement~~:~~

Respondents made suggestions for improvements across other areas for action in the draft Strategy. Some of the key improvements they called for are highlighted below.

Employment~~:~~

- Provide specialist training for Intreo staff to address the access needs of disabled people, including autistic people, beyond disability awareness training, and a target, such as 90% of staff trained.
- Focus on supporting autistic adults of all ages in accessing and maintaining employment, not just younger adults.

- Offer micro-grants through Local Enterprise Offices to support entrepreneurship and self-employment for autistic individuals and recognise their potential for innovation.

Acceptance and understanding campaign

- Ensure that stakeholders involved in the co-design of campaigns and initiatives include autistic individuals.
- Provide practical tips for the public on how to make various everyday contexts more inclusive for autistic people, such as in shops, restaurants and schools.
- Use diverse communication channels, such as podcasts, online video-hosting channels and social media apps, to enhance understanding and representation of autism.
- Emphasise understanding over simply awareness, and affirmation of neurodiversity over simply acceptance.

Early learning and childcare

- Act on the recommendations of the review of the Access and Inclusion Model (AIM) to improve the experience of autistic children accessing early learning and childcare programmes.
- Collect data on children in early learning and childcare settings about disability, ethnicity and gender to inform both mainstream and targeted measures.
- Provide equal access to financial supports and subsidies for families enrolling autistic children in early learning and childcare programmes.
- Clarify what constitutes "improved outcomes" under Action 5.4 of the draft Strategy and ensure that the guidance is developed in consultation with autistic professionals and that practices are neuro-affirming.

Parent support

- Ensure the new HSE autism information website includes information for parents at all stages of the assessment process (not just post-diagnosis), accommodates parents whose first language is not English, and addresses the capacity of public health nurses to support parents.
- Provide additional support services for parents to address carer burnout, older parents with autistic adult children, the need for respite and day services, and residential support and therapy for autistic individuals prone to violence.
- Expand training to support the parents of non-speaking children to other professionals beyond public health nurses, as they only work with children up to a certain age. Non-speaking children will need support and strategies to assist in their language development.

Access: built environment and design

- Engage with the private sector to encourage the creation of autism-friendly environments by offering sensory awareness training for professions involved in built environment design (e.g. architects, planners, designers and builders), as well as support and resources such as downloadable signage.

- Encourage businesses to implement autism-friendly practices, such as adjusting lighting and sound levels, displaying signage indicating staff are autism aware~~,~~ and designating autism-friendly days/times.
- Install quiet spaces, provide visual guides~~,~~ and use autism-awareness signage in all public buildings, offices~~,~~ and facilities.

Individual respondents: analysis of group differences

Among the 156 autistic individual respondents, the top five ranking of areas for improvement were:

1. Health and social care
2. Employment
3. Primary and post-primary education
4. Autism training

= 5. Understanding and acceptance campaign
= 5. Access: built environment and design

Among the 186 individual respondents who were parents and guardians of autistic people, of whom 44 also identified as autistic, the top five ranking of areas for improvement were:

1. Health and social care
2. Primary and post-primary education
3. Autism training

=4. Understanding and acceptance campaign
=4. Parent support

Among the individual respondents, both the group of 156 autistic people and the group of 186 parents and/or guardians of autistic people identified health and social care as the top area for improvement. Both groups also had the areas of primary and post-primary education, autism training, and the acceptance and understanding campaign in their top five areas for improvement. There were differences, however, between these groups. Notably, autistic respondents ranked employment as the second most important area for improvement and access to the built environment and design as the joint fifth. In contrast, parents and/or guardians of autistic people ranked parent support as the fourth most important area for improvement.

Ranking of proposed actions

Respondents were asked to rank by importance the top five areas for action in the draft Strategy based on those actions they felt could have the greatest positive impact. In the top five for both individual and organisational respondents were: health and social care, primary and post-primary education, and autism training. The top five for individual respondents also included the acceptance and understanding campaign and employment. The top five for organisational respondents included engagement with autistic people and early learning and childcare. The results are outlined below.

Ranking of actions by individual respondents

The top five most important areas for action identified by individual respondents were:

1. Health and social care (18%)
2. Education – primary and post-primary (13%)
3. Acceptance and understanding campaign (11%)
4. Autism training (10%), and
5. Employment (9%).

Under the 22 areas for action put forward in the draft Strategy, there are 70 individual actions. Among individual respondents, 42% ranked areas for action at the level of individual actions. The breakdown of their responses within the top five areas for action is detailed below.

Action 10: Health and social care

In the area for Action 10: Health and social care, the ranking by individual action was:

1. Action 10.2: To enable autistic children and adolescents to access early intervention and assessment measures, concerted efforts will continue to support early intervention and assessment services in disability services for autistic children (27%)
2. Action 10.4: To enable autistic children and adolescents to access appropriate mental health services, we will continue the development of early intervention and assessment services in primary care for autistic children will be continued (25%)
3. Action 10.1: To establish a public pathway to assessment and interventions for autistic adults, a demonstrator project will be rolled on in one Community Healthcare Organisation (21%)
4. Action 10.3: To begin building the extra service capacity required in specialist disability supports, we will advance the roll-out of the *Action Plan for Disability Services 2024–2026* (18%)
5. Action 10.5: To provide relevant mental health services to autistic adolescents and adults with substance use problems, we will progress the development of clear and integrated care pathways for people with a dual diagnosis (5%), and
6. Action 10.6: To ensure continuity of care and support for autistic people with particular vulnerabilities and increased risk of suicide, we will work with the HSE National Office for Suicide Prevention to scope and agree a range of suicide prevention initiatives (4%).

Action 6: Education – primary and post-primary

In the area for Action 6: Education – primary and post-primary, the ranking by individual action was:

1. Action 6.1: To ensure that all students, including autistic students, can learn in a safe and supportive environment, we will support the development and implementation of new behaviour of concern guidelines (48%)

2. Action 6.3: To ensure that parents and education professionals have access to autism best practice and training, we will review the service that the Middletown Centre for Autism is providing to schools, students and families (30%), and
3. Action 6.2: To provide opportunities for autistic students and others with special educational needs to engage with peers in both mainstream and special schools, we will support schools to implement the Towards Inclusion Programme (22%).

Action 1: Acceptance and understanding campaign

In the area for Action 1: Acceptance and understanding campaign, the ranking by individual sub-action was:

1. Action 1.2: To promote greater acceptance and understanding of autism in Ireland, we will initiate a national autism acceptance and understanding campaign on autism (87%), and
2. Action 1.1: To inform a national public acceptance and understanding campaign on autism, we will compile a synthesis of existing data on current attitudes towards autistic people in Ireland (13%).

Action 2: Autism training

In the area for Action 2: Autism training, the ranking by individual action was:

1. Action 2.5: To promote good practice in supporting autistic pupils in schools, we will raise awareness and provide training in order to advance the roll-out of the *Autism Good Practice Guidance for Schools* (24%)
2. Action 2.2: To promote neuro-affirmative models of practice in the health and social care sector, we will support the development and promotion of an autism training framework for professionals working with autistic people in the HSE and in Section 38 and 39 organisations (22%)

=3. Action 2.1: To promote understanding of autism across the public sector, we will ensure that development of a disability equality e-learning module includes consideration of the needs of autistic people (16%)

=3. Action 2.6: To ensure that the autistic experience is appropriately represented in the media, we will seek to promote and stimulate initiatives to support diversity in the media (16%)

=5. Action 2.3: To enhance the skills and competencies of staff in understanding autism, we will provide training on autism, including communication methods for frontline staff delivering the National Clinical Programme for Self-Harm and Suicide-related Ideation (11%), and

=5. Action 2.4: To better support autistic people in accessing health and social care services, we will provide training on the HSE’s National Guidelines on Accessible Health and Social Care Services (11%).

Action 8: Employment

In the area for Action 8: Employment, the ranking by individual action was:

1. Action 8.1: To enable employers to better support autistic employees in the workplace, we will review existing resources relating to autism-friendly workplaces (50%)
2. Action 8.2: To enhance our knowledge and understanding of autism and diversity in the recruitment market and the Irish civil and public sector, we will continue to gather equality monitoring data (19%)
3. Action 8.7: To support remote working and entrepreneurial opportunities for autistic people, we will encourage the development of autism-friendly workspaces within the Connected Hubs network (13%)

=4. Action 8.3: To better understand the needs of autistic candidates and others, we will collect data on reasonable accommodation requests and requirements (6%)
=4. Action 8.5: To ensure that Intreo (the Public Employment Service) effectively supports staff to address employment opportunities and challenges for people with disabilities, including autism, we will review and continue to provide disability awareness training to staff working in Intreo (6%), and
=4. Action 8.9: To ensure that all employees in the civil and public sector can carry out their work on an equal footing, we will ensure that consideration is given to the needs of autistic staff, along with other cohorts, in the review of reasonable accommodation policy and procedures (6%).

Individual respondents: analysis of group differences

Among the 156 autistic individual respondents, the breakdown of the top five areas for action, in order, were:

1. Health and social care
2. Education – primary and post-primary
3. Employment
4. Autism training, and
5. Acceptance and understanding campaign.

Among the 186 parents or guardians of autistic persons, the breakdown of the top five areas for action, in order, were:

1. Health and social care
2. Education – primary and post-primary
3. Acceptance and understanding campaign
4. Autism training, and
5. Employment.

Both the group of 156 autistic respondents and the group of 186 parents and/or guardians of autistic people ranked the same top five areas of importance as the whole set of 334 individual respondents. These were: health and social care, primary and post-primary education, autism training, the acceptance and understanding campaign, and employment. All groups ranked health and social care and primary and post-primary education as the first and second most important areas for action, respectively. It is notable, however, that autistic respondents ranked employment as the third most important area for action, which is higher than the fifth place afforded this area by both parents and guardians of autistic people and the broader group of all 334 individual respondents.

Ranking of actions by organisational respondents

Analysis of the top five areas for action in the draft Strategy identified by organisational respondents produced the following ranking:

1. Health and social care
2. Autism training

=3. Education – primary and post-primary
=3. Engagement with autistic people, and
5. Early learning and childcare.

The priorities expressed by organisational respondents were similar to those for individual respondents. Both groups had health and social care as their most important area for action, and had autism training and education – primary and post-primary in their top five. The other actions in the top five for organisations were engagement with autistic people and early learning and childcare.

Only 13 organisations answered this question, and of these only 6 provided responses which ranked areas for action at the level of individual actions. As such, there are insufficient data to draw firm conclusions about how organisational respondents ranked individual actions in their top five areas for action. It is notable, however, that organisations favoured actions 10.2 and 10.4 under health and social care, and action 6.1 under education – primary and post-primary. These mirror the preferences among individual respondents in these areas for action.

Acceptance and understanding campaign: target audience

To inform delivery of an action focused on rolling out an autism acceptance and awareness campaign under the Autism Innovation Strategy, respondents were asked which group from a given list should be targeted in any acceptance and understanding campaign.

For individual respondents the breakdown was: the general public 144 (43%), professionals working in an education setting 66 (20%), professionals working in a health and social care setting 58 (18%) and public sector workers 17 (5%). The submissions from organisations identified a range of target groups.

Some organisational and some individual submissions emphasised that an effective national campaign on autism should target a range of audiences and that each target group requires tailored messaging.

Individual respondents: target groups

Individual respondents were asked to choose one target group that they felt would be most important to target as part of an acceptance and understanding campaign on autism from a list provided. The breakdown, in order, was:

1. The general public 144 (43%)
2. Professionals working in an education setting 66 (20%)
3. Professionals working in a health and social care setting 58 (18%)
4. Other (please specify) 47 (14%), and
5. Public sector workers 17 (5%).

The 47 respondents who chose “other” were asked to elaborate. The breakdown of their preference for the campaign target groups was: all of the specified categories (21), a combination of two of the categories (11), autistic persons and their families (4) and employers (4). 7 respondents expressed concerns over a potential campaign, questioning the use of resources for the campaign (4) and the stigma it might cause (3).

Among the 156 individual respondents who identified as autistic, 155 indicated their preferred target group in any public acceptance and understanding campaign. The breakdown of their preferred target group, in order, was:

1. The general public 65 (42%)
2. Professionals working in a health and social care setting 40 (26%)
3. Other (please specify) 25 (16%)
4. Professionals working in an education setting 18 (12%), and
5. Public sector workers 7 (5%).

Autistic respondents were aligned with all individual respondents in identifying the general public as the most important group to target in any autism acceptance and understanding campaign. Unlike the group of individual respondents as a whole, however, autistic respondents gave a higher priority to the targeting of professionals working in health and social care settings as their second-preferred choice.

Of the 186 individual respondents who identified as parents or guardians of an autistic person, 185 indicated their preferred target group in any acceptance and understanding campaign. The breakdown of their preferred target group, in order, was:

1. The general public 77 (42%)
2. Professionals working in an education setting 49 (27%)
3. Other (please specify) 26 (14%)
4. Professionals working in a health and social care setting 22 (12%), and
5. Public sector workers 11 (6%).

Parents and guardians of autistic people were aligned with all individual respondents and autistic respondents in identifying the general public as the most important group to target as part of an acceptance and understanding campaign.

As their second-choice target group, parents and guardians of autistic people favoured the targeting of professionals in education settings, whereas autistic respondents favoured the targeting of professionals in health and social care settings.

Organisational respondents: target groups

A range of target groups were identified in the submissions from organisations, including:

- The general public
- Schools and educators
- Government and policy-makers
- Older people (aged 50+ years)
- Employers
- Youth clubs
- Community organisations
- Public services
- Health and social care staff
- Researchers
- Parents
- Students
- School-aged children, and
- Marginalised communities, such as the Traveller and Roma communities.

Target audiences and tailored messaging

Among respondents, many organisational and some individual submissions emphasised that an effective national campaign on autism must target a range of audiences, sometimes prioritising those with most influence over the desired outcome:

> "In our opinion, we would say that in designing an acceptance and understanding campaign on autism, it's crucial to target a wide range of groups to maximise impact and promote inclusivity. However, certain groups may be particularly important to prioritise due to their influential role in shaping societal attitudes and behaviours towards autism." (health and social care organisation)

In addition, respondents emphasised that each target group selected for an autism campaign requires tailored messaging:

> "If you focus on the general public, you may reach all of the above [professionals working in an education setting; professionals working in health and social care settings, and public sector workers]. In reality, each needs their own specific campaign as different levels of understanding are needed depending on the group." (autistic person).

> "For a national campaign to be effective, it has to speak to a range of audiences and messaging should be tailored accordingly." (organisation that supports autistic people)

> One organisation suggested how the messaging could be tailored for the general public, schools and educators, and government and policymakers:

"General Public: Educating the general public is vital for dispelling myths and stereotypes surrounding autism. This includes raising awareness about the diversity within the autism spectrum and promoting acceptance and inclusion.

Schools and Educators: Teachers and school staff play a significant role in supporting autistic students. Providing training and resources to educators can help create inclusive learning environments where autistic students can thrive. Initial teacher education, SNA training and autistic voice to inform training are key markers for success in this strategy.

Government and Policy Makers: Advocating for policies and legislation that promote the rights and inclusion of autistic individuals is essential. This may include advocating for better access to healthcare, education, employment, and support services.” (statutory body)

Another organisation suggested the need for a target side-campaign with tailored-messaging focused on three specific groups: older people; employers, youth clubs, and community organisations; and public services.

Acceptance and understanding campaign: key messages

Respondents were asked to identify the most important message to communicate as part of an acceptance and understanding campaign about autism. Key messages were identified using a thematic analysis of the data provided by all submissions both from individuals and organisations. This analysis generated five key messages:

- Challenge misconceptions and stereotypes
- Raise awareness of inclusive practices
- Highlight individual rights and equality
- Emphasise diversity within autism
- Explain and support neurodiversity.

Each key message is outlined in further detail below.

Challenge misconceptions and stereotypes

Respondents felt a campaign should challenge common misconceptions and stereotypes about autism and autistic people and promote a positive, accurate and intersectional representation of autistic experiences and narratives:

> “We need to move away from historical views on autism, deficit-based and medical model approaches. The campaign needs to highlight the amazing parts of being autistic, the positive attributes, that autistic people can live full independent lives if the right supports are accessible. The campaign should reflect diversity.” (autistic person; parent of an autistic person)
>
> “Counter the stereotypes, don’t reinforce them. It’s not about extremes in intelligence (high or low). It can be any gender, age or race.” (autistic person; close family member of an autistic person)
>
> “It should aim to challenge the myths around autism (e.g. eye contact, sociability, alternative communication, ‘autism wasn’t around in my day’, area of sensory difficulties, strain of masking) and it should also focus on celebrating difference.“ (organisation that supports autistic people)

Raise awareness of inclusive practices

The campaign should raise awareness of inclusive practices by offering advice on how to create autism-inclusive communities, particularly in schools, work settings and public spaces:

> "Something that doesn't bother one person can bother someone else, and accommodations for autistic people can actually make everyone's life easier". (autistic person; close family member of autistic person)
>
> "Tá sé tábhacht feasacht a ardu maidir le…bealaí ar féidir linn ar fad tacú le difríochtaí céadfaí, foghlama agus cumarsáide éagsúla sa saol laethúil agus conas timpeallachtaí égsúla a chur in oiriúint do na riachtanais sin (soilsiú, fuaim, sosanna gluaiseachta etc.)." (organisation that supports autistic people; original text in Irish)
>
> "It is important to raise awareness…to the ways in which we can all support sensory, learning and communication differences in everyday life and how to adapt different environments to these requirements (lighting, sound, movement breaks etc.)." (organisation that supports autistic people; translated from original in Irish)

Highlight individual rights and equality

The campaign should highlight that autistic people have the same rights as all other citizens and advocate for their inclusion, especially when calling for better access to public services:

> "As an autistic person, I expect others to treat me as a human being, accorded with the rights and privileges of any other citizen. I should not be expected to wait my entire life while society decides to 'accept' me, and by association, my autism." (autistic person)
>
> "The key message for any communication in relation to Autism is that each person is an individual with the same rights as all other citizens in line with the UNCRPD." (organisation that supports autistic people)

Emphasise diversity within autism

The campaign should emphasise the range of diversity among autistic individuals, including differences in strengths, challenges, communication styles and support needs:

> "It would be fantastic if there was some education done on the diversity within the autistic spectrum. Anyone who doesn't fit into the niche expectation that people have when they think of autism (a non-speaking autistic child with a learning disability) are still having difficulties being believed and getting the support that we need. It's important for people to know that that is just one presentation of autism and that it's truly as varied as the experiences of allistic/non-autistic people." (autistic person)
>
> "Educating the general public…includes raising awareness about the diversity within the autism spectrum and promoting acceptance and inclusion." (statutory body)

Explain and support neurodiversity

The campaign should explain neurodiversity and encourage people to embrace the understanding that different ways of processing and experiencing the world offer unique strengths and perspectives:

> "Communicate to neurotypical people that autistic people are just like neurotypical people except that the brains of autistic people are wired differently so that there are some things that autistic people struggle with, but [they] are excellent with other things that neurotypical people struggle with. Also provide examples of what each group struggles with, and what each group of people excel at, e.g. attention to detail for autistic people, social skills for neurotypical people....In the campaign, emphasise that autistic people are not worse than neurotypical people, just different, and that diversity should be celebrated and embraced, not humiliated, bullied and penalised." (autistic person)

> "That our brains are just different, not lesser....Highlight the 'double empathy' issue and that up until now, the onus has been on the autistic person to be always conscious of making the [neurotypical] person comfortable and never the other way around, which needs to change." (autistic person; parent/guardian of an autistic person)

> "Tá sé tábhacht feasacht a ardu maidir le néara-éagsúlacht i gcoitinne agus bealaí ar féidir linn ar fad tacú le difríochtaí céadfaí..." (organisation that supports autistic people; original text in Irish)

> "It is important to raise awareness in relation to neurodivergence in general..." (organisation that supports autistic people; translated from original in Irish)

Other messages identified

The five key messages outlined above were shared across the two groups of respondents, individuals and organisations. There were, however, some notable differences between the two groups in terms of the thematic analysis of key messages identified outside of the top five. In addition to the five key messages, individual respondents also wanted the campaign messaging to:

- Foster empathy, kindness, and compassion towards autistic individuals while discouraging judgement, stigma and discrimination.
- Encourage collaboration and partnership between autistic individuals, their families, professionals and policy-makers to create supportive environments.

Organisations, on the other hand, in addition to the five key messages identified, wanted to the campaign messaging to also:

- Empower the voices of the autism community through the inclusion of their lived experiences in the campaign.

Other comments

In addition to the questions outlined above, respondents were given the opportunity to raise other comments in relation to the draft Autism Innovation Strategy. Most of these comments cut across the areas for action. These included calls for actions which improved co-ordination and collaboration between public services, a desire for measurable outputs and details of funding for the Strategy, legislation to reinforce the rights of autistic individuals, a greater focus on autistic women and girls, a stronger focus on autistic adults, and the rejection of behavioural interventions. Several respondents also highlighted additional areas they felt should be covered by the draft Strategy. The key aspects of these "other comments" are detailed by theme below.

It is also important to acknowledge that some respondents expressed scepticism about the Strategy's ability to deliver. First and foremost, they emphasised the urgency of addressing key challenges for autistic people and their families, such as waiting lists for services and assessments.

Increased co-ordination and collaboration

- Some respondents called for improved co-ordination and coherence of supports for autistic people, with suggestions for a "one-stop" shop for autism supports and services.
- Several respondents emphasised the need for more integrated public services and for the interplay between different services to be clearly articulated.

Measurable outcomes and funding

- Several respondents highlighted that a number of actions are difficult to measure because there is no clear output. It is suggested these actions would benefit from incorporating a way to measure effectiveness.
- Although aware of the 18-month time frame of the Strategy, several respondents raised concerns over the proposed actions having few deadlines attached.
- Some respondents noted the significant costs associated with some of the actions outlined and cautioned that the Strategy requires a budget and allocation of financial resources.
- There were calls for the Strategy to have a longer time frame in order to have a more meaningful impact and for some prioritisation of proposed actions.

Legislation

- Several respondents, particularly among the organisational submissions, called for the Strategy to be underpinned by legislation to ensure the actions outlined are adhered to by Government Departments and bodies.

Representation of autistic women and girls

- Several respondents highlighted the under-diagnosis of autistic people who were assigned female at birth, due to the different presentation of autism in the female population.
- More than simply being underdiagnosed, a number of respondents emphasised that autism among those assigned female at birth is often misdiagnosed because of differences in presentation.
- Respondents called for a specific focus on female autism in the Strategy, especially in the training of health professionals and any autism campaigns.

Autistic adults

- A number of respondents felt the draft Strategy was unevenly balanced towards children and younger adults at the expense of older adults.
- Improved access and provision of services for autistic adults were called for in relation to disability support, mental health support and assistive technology.

Rejection of behavioural interventions

- Several respondents called for an official review and regulation of behaviour-modifying interventions for autistic people in Ireland as these are perceived as harmful (e.g. Applied Behavioural Analysis (ABA) and Positive Behaviour Support (PBS)).
- Some respondents wanted the draft Strategy to make an explicit commitment that behavioural or compliance-based interventions should not be used for autistic people and to discuss ~~its~~ their harmful impact.
- In the context of education, it was highlighted that Action 2.2 discusses the promotion of neuro-affirmative models but fails to acknowledge that this would require the discontinued use of ABA/PBS and compliance-based therapies/approaches. Equally, Action 2.5 refers to compliance-based approaches which were felt by some respondents to be non-neuro-affirming.

Other areas

- Some respondents highlighted the lack of actions in the draft Strategy on housing and supported living. They called for local authorities' housing guidelines to recognise autistic people as a priority group who may require supports from the state to live outside the family home. Some respondents emphasised the need for the Strategy to consider intersectional issues, including race, ethnicity, gender non-conforming, immigration and membership of the Traveller and Roma communities.
- A number of respondents emphasised the need for the draft Strategy to consider safeguarding issues, as some autistic people – particularly those who are non-speaking – may be more vulnerable to abuse and be less lightly to report it.

- Some respondents highlighted the importance of political participation and the need to address voting and candidacy issues for autistic people.