

Written submission in relation to draft Autism Innovation Strategy

Please answer the questions below and submit to <u>Autism Strategy@equality.gov.ie</u> by 4pm on **Friday 1**st **March at 2024.**

The word limit for written submissions is <u>2000 words</u>. Please stick to this limit. An A4 page with single spaced text font 12 is between 400 and 500 words.

Please focus on responding to the specific questions asked.

Written submissions from organisations should clearly indicate how many members were consulted in preparation of the submission.

Individuals who are not part of an organisation and would like to make a written submission are welcome to do so.

Thank you for your input.

out you	
1. Are you an autistic person? (Guidance: This includes people wit without a formal diagnosis of autism)	th an
Yes	
No X	
I don't know	
Prefer not to say	
2. I am responding as:	
An autistic individual	
 A representative of a Disabled Persons Organisation If yes, please specify your name and the name of the organisation: 	
 A representative of another organisation that supports autistic people If yes, please specify your name and the name of the organisation: 	е
Rebecca Gorman	
Pavee Point Traveller and Roma Centre	
Rose Marie Maughan	
Irish Traveller Movement	

•	A health and social care professional	
	If yes, please specify the name of the organisation:	
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		-
•	An education professional	
	If yes, please specify the name of the organisation:	
		7
•	A representative of a statutory organisation	
	If yes, please specify your name and the name of the organisation:	
		7
		<u></u>
•	The parent or guardian of an autistic person	
•	The carer of an autistic person	
•	A close family member of an autistic person	
•	Supporting an autistic person to complete this written submission	
2	If you are responding on behalf of an organisation, please indicate how	
J.	many members were consulted in preparation of this submission:	
_		1
- 1		1

only,	please indicate your age-group:
18-24	
25-49	
50-64	
65-79	
80 or more	
Prefer not to say	

4. If you are responding as an autistic person or a parent or guardian

Questions on draft Autism Innovation Strategy

You are being asked to share your views on the draft Autism Innovation Strategy before it is finalised and launched.

The Autism Innovation Strategy aims to address the bespoke challenges and barriers facing autistic people and to improve understanding and accommodation of autism within society and across the public system. The Autism Innovation Strategy contains actions that will be undertaken right across Government to better support autistic people and their families. The Strategy will have an 18-month lifespan and it is important that actions under the strategy can be delivered within this 18-month period.

While the Autism Innovation Strategy will focus on addressing bespoke challenges and barriers facing autistic people and their families, there are wider actions underway to effectively address the shared challenges facing people with disabilities more broadly.

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. A new National Disability Strategy is also being developed to provide a blueprint, developed in partnership with disabled people, for continued implementation of the UNCRPD in Ireland and to further support the rights and inclusion of all disabled people.

The Autism Innovation Strategy will complement and enhance wider disability efforts by focusing on areas where there are bespoke needs for autistic people.

As the questions in this document focus on the draft strategy, it would be helpful to have a copy of the draft Autism Innovation Strategy with you when you prepare your written submission.

At the end of this consultation, there will be a report. The final version of the Autism Innovation Strategy will also be published.

Innovation Strategy is clear and accessible? (300 words) Yes. Other associated materials and publications made in relation to the strategy should also be available in plain English.

• Question 1: Do you feel that the language used in the draft Autism

• Question 2: Please identify one thing you liked about the draft Autism Innovation Strategy. (300 words)

The Strategy seeks to align with existing Government strategy; it is underpinned by Human Rights law, particularly the UNCRPD, broader alignment with other policies required (e.g.) National Plan Against Racism, forthcoming National Equality Data Strategy, etc. Public Sector Equality and Human Rights Duty as per Section 42, IHREC Act 2014 must be included.

 Question 3: Are there any actions in the draft Autism Innovation Strategy that you think could be improved? Please indicate up to three actions that you think it would be most important to improve and why. Please include reference to the relevant action numbers in your response. (400 words)

Overall the Strategy need to ensure a focus on, and reference to, intersectionality.

Other actions include:

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.

A key gap exists in Ireland as related to equality data as related autistic people. We are not aware of data on the attitudes towards autistic people in Traveller and Roma communities and/or autistic Travellers and Roma. Again, focus on intersectionality is required as per the National Action Plan Against Racism.

2.1. To promote understanding of autism across the public sector, we will ensure that development of a new disability equality e-learning module includes consideration of the bespoke needs of autistic people alongside groups with other types of disabilities. Furthermore, we will ensure that autistic people are consulted in the development of this module. This foundational learning tool will provide a basis for the development of further sector-specific training and supports in order to make public services more disability and autism-friendly.

Consultation and direct engagement with NGOs, including Traveller organisations, working with autistic people will be vital to the development and delivery of this work and resourcing will be required.

Reference to the private sector to be included as there are positive models to be drawn on. The State has a role to play in informing these bodies of best practices in these areas – autistic people also engage in these sectors.

5.1. To support the inclusion of autistic children in mainstream early learning and childcare, we will ensure that professional support and advisory services include guidance around the needs of autistic children.

This action requires robust disaggregated data in order to inform both mainstreaming and targeted measures. We understand that that DCEDIY have made some progress in this area, however, implementation of ethnic equality monitoring across all routine administrative data collection systems, inclusive of disability, ethnicity and gender is required.

Specialist staff and adequate pay should be prioritised to ensure the workforce has the capacity to provide the best care possible is provided to autistic children. In terms of meeting the needs of autistic Traveller and Roma children specialist staff must undergo mandatory in-service anti-racism and discrimination training. It is also vital both Traveller and Roma are invested in so that they too are among the specialist staff working with autistic children.

Question 4: Please rank the five actions under the Strategy which you
consider to be most important and which could have the greatest positive
impact (With 1 being most important). Please include reference to the
relevant action numbers in your response (200 words)

1.	10.2 To enable autistic children and adolescents to access appropriate therapy supports, concerted efforts will continue on the development of measures to support early intervention and assessment services in disability services for autistic children, guided by a shared care approach.
2.	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 for schools.
3.	9.1. To ensure that the support needs and preferences of persons with a disability, including autistic people, are included in the development of a guidance document that will support and enable people with a disability to engage in effective decision-making about the design and implementation of their HSE-funded support services, we will co-design the guidance document with persons with a disability, including autistic people, and other stakeholders.
4.	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, guided by a shared care approach.
5.	11.1 To provide clear and accessible information to support autistic people and their families, we will develop information on the HSE website and in printed brochure form on common conditions associated with autism and neurodivergence, and will include local signposting information for how and where autistic people, along with others, can access support services.

 Question 5: Action 1.2 in the Strategy is about running an acceptance and understanding campaign on autism. Which group do you think it would be most important to target as part of an acceptance and understanding campaign on autism? What key message should a campaign about autism seek to communicate? (200 words)

Suggesting reframing this as an awareness raising campaign framed within a human rights based approach. At present Autistic Traveller and Roma adults are invisible within the mainstream, society and the public awareness campaigns, policy structures developing policy impacting on their lives this needs urgent attention therefore it is crucial both communities are targeted in any acceptance and understanding campaigns, Traveller/Roma organisations need to be resourced to support this work.
Affirming autism acceptance in the Traveller and Roma communities and supports available to families and young people is of critical importance, both to promote the quality of life of autistic people in the Traveller and Roma communities, while also promoting the safety and efficacy of vaccinations (where disinformation exists of links between vaccines and the development of autism).

Question 6: Do you have any other views on the draft Autism Innovation Strategy? (600 words)

- Lack of equality data available of the incidence of autism in Travellers and Roma communities. Commitment to implementing ethnic equality monitoring (inclusive of gender, disability & ethnicity) in order to inform the Strategy and its actions to provide inclusive and intercultural services and information to minority ethnic groups, who may have different views and experiences of autism in their communities.
- 2. Need for a social determinants of health approach and need to have an integrated approach. There are no actions relating to the Department of Housing and Local Government. Local Authorities play a large role in local infrastructure and should be involved in the work of the Strategy to ensure its impact is felt at a local level. An example is the need to ensure a health-lead, human rights approach, incorporating the needs of autistic people, is included in the Traveller Accommodation Programmes developed by Local Authorities to ensure they are fit for purpose.
- 3. Actions should also incorporate community work-based approaches, to ensure sustainable practices that engage with marginalised communities work effectively-as per <u>Sustainable</u>, <u>Inclusive and Empowered Communities and Values and Principles for Collaboration and Partnership</u>. There is an intersectionality with the adverse experiences of autistic people such as exclusion, addiction, discrimination and the same experiences for Travellers and Roma, where these experiences are further compounded by being marginalised in Irish society. One of the most striking examples is the practice of reduced timetables for children that disproportionately affect Traveller and Roma children, including Traveller and Roma children with disabilities.

In its existing state, this Strategy will further widen the gaps for disadvantaged groups without targeted actions in place to address existing structural inequalities. Further actions targeting specific disadvantaged groups are required to ensure there will be an equity of outcomes of the actions outlined in the Strategy to ensure this happens Traveller/Roma organisations must be resourced to work with autistic members of their communities as a measure to support their participation with policy forums impacting on their lives.