

Written submission in relation to draft Autism Innovation Strategy

Please answer the questions below and submit to Autism\_Strategy@equality.gov.ie by 4pm on **Friday 1st March at 2024.**

The word limit for written submissions is 2000 words. 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.

# About you

## Are you an autistic person? (Guidance: This includes people with and without a formal diagnosis of autism)

Yes

X

No

I don’t know

Prefer not to say

## 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:

XX

* A health and social care professional

If yes, please specify the name of the organisation:

Dublin Rape Crisis Centre (DRCC). The mission of DRCC is to prevent the harm and heal the trauma of all forms of sexual violence in Ireland. DRCC has been at the forefront of the Irish response to sexual violence for more than 40 years.

* An education professional

If yes, please specify the name of the organisation:

* A representative of a statutory organisation

If yes, please specify your name and the name of the organisation:

* 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
1. **If you are responding on behalf of an organisation, please indicate how many members were consulted in preparation of this submission:**

DRCC’s We~Consent campaign have been collaborating with AsIAm. The We~Consent team, worked with them to run 2 qualitative focus groups, one for parents of autistic children and another for autistic adults.

1. **If you are responding as an autistic person or a parent or guardian only, please indicate your age-group:**

18-24

25-49

50-64

65-79

80 or more

Prefer not to say

# 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.

## Question 1: Do you feel that the language used in the draft Autism Innovation Strategy is clear and accessible? (300 words)

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.

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. Offering a version that's easy to understand makes everyone feel included and helps more people grasp and get involved with the content. Ultimately, this makes the draft Strategy more effective in reaching a wide range of stakeholders. (127)

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

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.

The inclusion of an easy to read version of the draft Strategy promotes the participation and engagement of autistic people, their families, caregivers, and other stakeholders who may benefit from the simplified language and clear presentation of information. It also empowers autistic people to have a voice in shaping the strategy and participating in decision-making processes related to their well-being. By making the content understandable and user-friendly, the easy to read version encourages active participation and self-advocacy. (116)

## 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)

**Action 6: Education** Tailored Relationship and Sexuality Education (RSE) for autistic children, young people and adults should be included within this action item.

Research shows that the lack of sexual knowledge is a key predictor of sexual victimisation, with actual knowledge partially mitigating this risk. Consequently, accurate and inclusive RSE is essential. The Autism Good Practice Guidance for Schools released in 2022 highlighted that RSE for autistic children and young people needs special considerations to account for social communication and sensory processing differences. The guidance states that The National Council for Special Education (NCSE) and Middletown Centre for Autism (MCA) provide Teacher Professional Learning (TPL) on RSE. The guidance also states that parents play a vital role in providing information and education in this area.

While no formal research exists within Ireland, international research found that caregivers and parents report dissatisfaction with sex education for autistic people, citing a lack of autism accommodations in school content. Consequently, primary responsibility for sexual education often falls on parents and caregivers. Teachers need support and training in order to provide this education in a safe and accessible way.

**Action 20: Data** There is little to no Irish research, qualitative or quantitative on the prevalence of sexual violence experience of autistic people. The CSO sexual violence survey statistics from 2022 highlighted that people with a disability experienced sexual violence as an adult at a higher rate (30%) than those without a disability (25%) however these statistics did not give further details regarding the disabilities.

Current international research highlights the heightened vulnerability of autistic people, particularly those with higher support needs, to sexual victimisation. In a 2022 study, 75.4% of autistic adults reported experiencing sexual harassment, and nearly 60% reported experiencing sexual violence, surpassing rates among non-autistic individuals. Similarly, to the general population, autistic women and girls are at a higher risk of sexual victimisation. An online survey found that up to nine autistic women out of ten have experienced sexual violence, with 75% reporting the onset during childhood or adolescence.

We need to acknowledge the heightened risk of experiencing sexual violence within the autistic population. Research is needed into this area to ascertain the intersections of autism and sexual violence victimisation and perpetration to provide an evidence-based approach to preventing harm. This should be included in **Action 22: Research** and be considered throughout Action 20: Data. (392)

## 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)

**Action 6 Education:** Autistic people often face unique challenges in understanding and navigating relationships and sexuality due to differences in communication, social interaction, and sensory processing. Incorporating tailored RSE that covers topics such as consent, boundaries, communication skills into the draft Strategy is essential to equip autistic young people in particular, with the knowledge and skills to recognise and respond to unsafe situations and to empower them to develop healthy relationships and make informed decisions about their personal lives.

**Action 2 Autism training**: Autism training for stakeholders within the Domestic, Sexual & Gender-Based Violence (DSGBV) sector including **Court Services** (**Action 4)** can help them understand how trauma can intersect with autism and how to provide sensitive and appropriate support that respects the individual's communication preferences, sensory sensitivities, and coping mechanisms.

**Action 10 Health and Social Care:** Incorporating references to the supports and services provided by the DSGBV sector within this action is crucial to ensuring comprehensive support for autistic people who have experienced sexual harm. It ensures that autistic people who disclose sexual harm, receive tailored care and support and that the intersectionality of autism with other needs and experiences are also attended to.

**Action 11 Information**: Ensuring autistic people and their families and/or caregivers have access to information about the services and supports of the DSGBV sector that are clear and accessible, should be included within this action. (229)

## 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)

There are people and organisations better placed than DRCC to address this important aspect of the draft Strategy. 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. (71)

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

We-Consent is a long-term national campaign that we in DRCC are engaged in, to inform, educate and engage with all members of society about consent.  Through our work in building more awareness of each other’s experiences, we have been collaborating with Ireland’s leading Autism charity, AsIAm to carry out research. They indicated that they also receive a significant number of requests for information and resources on consent that they are currently not able to provide.  Our research aims to increase an understanding of what autistic people and their families think and feel about consent by exploring consent communication, consent education and how these topics interact with their neurodiversity.

To do this we worked together to run qualitative focus groups for two groups with AsIAm. The reports are still in the process of being produced, however, clear themes emerged throughout.

**Parents** have concerns for the vulnerability of autistic children, a huge lack of support for parents in providing consent and sexual health information for their children, frustrations over the lack of acceptance of autism in society.

**Autistic** adults are frustratedover a lack of accessible services, information and resources regarding relationships and sexual health and sexuality. Frustration over being infantilised. Distrust of services who do not understand autism.

Through our work and the early stages of our research, it is clear that autistic people and those who support them are facing a gap in education, supports and resources about sex, sexuality, consent and relationships. It is also clear that when sexual harm occurs, partially due to this gap in information, autistic people and their families are unsure of where they can access help and how they will be treated if they do. The draft Autism Innovation Strategy must take into consideration these gaps, alongside the heightened vulnerabilities of autistic people, and take steps to bridge them. Sexual health, sexuality and consent need to be included in the strategy in meaningful ways alongside the inclusion of steps to improve services if and when sexual harm occurs. (334)