



Department of
Health

An Roinn Sláinte

Máinnystrie O Poustie

www.health-ni.gov.uk

AUTISM PRIORITIES 2023-2028

Have your say....

AUGUST
2021

INTRODUCTION

In March 2021, the Minister for Health, Robin Swann MLA, published an Autism – Interim Strategy for the years 2021 and 2022 with the commitment to commence development of a further longer term Autism Strategy 2023-2028. A link to the interim Autism Strategy is provided below.

[Autism – Interim Strategy 2021-2022 | Department of Health \(health-ni.gov.uk\)](https://www.health-ni.gov.uk/autism-interim-strategy-2021-2022)

Work on a longer term strategy is about to commence and in bringing together a people-centred strategy which can support and improve the lives of autistic people, and those who may be waiting for an assessment, the Department of Health wants to hear from you to ensure that the priorities of this strategy will reflect the needs of the people of Northern Ireland.

We would be grateful if you would take this opportunity to answer the questions in this document. You do not need to answer all the questions, but it would be helpful if you could provide as much detail as possible. If required, you may want to ask a representative from a support organisation to help you in completing the form.

If you are unable to answer the questions, but want to send us general comments, you can use the 'Additional Comments' section at the end of the form.

**We look forward to hearing from you.
Please send your response by 8th October 2021.**

Personal Information

Whilst the department looks forward to receiving your views we would ask that your response remains anonymous and that no personal data is disclosed in your responses to this document.

Thank you.

Question 1	
<p>Tell us what you think the 4 key priorities should be for the next Autism Strategy in Northern Ireland in 2023, for example, Assessments, Early Intervention, Education, Employment or perhaps Independent Living.</p> <p>Please list in order of importance to you.</p>	
1	<p>Independent scrutiny of the implementation of the Autism Strategy.</p> <p>Arrangements for independent scrutiny would help address the lack of consensus among stakeholders about the effectiveness of the recent strategy and action plan and build trust/confidence in the transparency of the arrangements for the forthcoming strategy.</p>
2	<p>Addressing delays in diagnosis through reducing waiting times.</p> <p>Article 25 (b) of the United Nations Convention on the Rights of Persons with Disabilities requires the provision of ‘those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons’.</p>
3	<p>Inclusion of quantifiable targets.</p> <p>Article 4 (2) of the United Nations Convention on the Rights of Persons with Disabilities requires that ‘with regard to economic, social and cultural rights, each State Party undertakes measures to the maximum of its available resources...’</p>
4	<p>Provision of early intervention services (available within a 3-6 week period).</p> <p>Article 25 (b) of the United Nations Convention on the Rights of Persons with Disabilities requires the provision of ‘those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons’.</p>

**Additional
Comments**

Delivering an Effective Strategy

With regards to the design and delivery of the strategy, we recommend that the Department:

- ensures that the strategy sets out **how the Executive intends to contribute to the delivery of the full range of obligations placed on the State under the [United Nations Convention on the Rights of Persons with Disabilities](#)**, with any prioritisation of key strategic priorities on the basis of identifying those that will have the greatest positive impact on autistic people;
- **secures the pro-active, effective participation of autistic people**, including children and young people, in the implementation of the Strategy and Action Plan;
- **explicitly allocates appropriate resources** to deliver the strategy;
- **develops an action plan and monitoring framework**, including targets that are specific, measurable, achievable, realistic and time-bound, so as to deliver **significant positive impacts** for autistic people;
- **collect sufficient data relating specifically to autism in Northern Ireland** and publish it in an appropriately disaggregated and accessible format to ensure the effective design and monitoring of the strategy;
- **identifies explicit governance and delivery mechanisms**, including explicit **responsibility** for leading on the delivery of the specific elements of the strategy and structures to co-ordinate actions by Departments with a role in promoting and protecting the rights of autistic people and hold them accountable for progress against strategic targets;
- ensures that the strategy **addresses issues of multiple identity** and associated disadvantages and needs;
- **sets out an independent review process in order to evaluate the extent to which the objectives of the Autism Strategy have been met** by the end of the proposed timeframe and consider the need for a further action plan to meet any objectives not realised.

Question 2

How can we practically involve people with lived experience of autism in developing the next Autism Strategy?

Comments

Through the creation of an effective Forum to assist, oversee the development, implementation and review of the Strategy and to keep the effectiveness of the policy and practice regarding services for autistic people under review, identify best practice and suggest changes to policy and practice where the evidence suggests that this is necessary.

The Forum should reflect the full autistic spectrum and include adults and young people with autism reflective (as far as possible) of the equality categories set out in [Section 75](#) of the Northern Ireland Act 1998, representative NGOs and DPOs, parents and carers as well as officials from, key Departments such as Health, Communities and Education etc.

[Article 4\(3\)](#) of the [United Nations Convention on the Rights of Persons with Disabilities](#) requires that 'In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations'. The UN Committee on the Rights of Persons with Disabilities provides further information on the participation of disabled people in the policy development process in its [General Comment No.7](#)

[Article 1](#) of the Convention sets out that 'Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others'.

Question 3

What changes would you like to see in our services, our communities and our society as a result of the Autism Strategy?

Comments

Services:

- Strong leadership from the Department of Health in the development, co-ordination and implementation of the new autism strategy and action plan;
- Autism awareness and disability equality training provided for all relevant public authority frontline staff as well human resources and key policy making staff. [Article 25](#) (d) of the [United Nations Convention on the Rights of Persons with Disabilities](#) requires 'health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and promulgation of ethical standards for public and private health care'. Provision of uniform and equal access to autism services across the region (eliminate postcode lottery). [Article 25](#) (c) of the [United Nations Convention on the Rights of Persons with Disabilities](#) requires the provision 'of health services as close as possible to people's own communities, including in rural areas'.
- Mental health services that meet the needs of autistic adults and children ([Autistica](#), the UK's autism research charity, reports that autistic adults who do not have a learning disability are 9 times more likely to die from suicide and that children with autism are 28 times more likely to think about or attempt suicide).
- Positive action programmes providing support to ensure the full inclusion of autistic people in all aspects of society including education, employment, healthcare, leisure etc. in accordance with the rights set out in the [United Nations Convention on the Rights of Persons with Disabilities](#)

Community and Society:

- A multi-level awareness raising campaign on the needs and rights of autistic people.

[Article 8](#) of the [United Nations Convention on the Rights of Persons with Disabilities](#) requires that the State Party undertake to adopt immediate, effective and appropriate measures:

- 1 (a) To raise awareness throughout society, including at the family level, regarding persons with disabilities, and to foster respect for the rights and dignity of persons with disabilities;
- (b) To combat stereotypes, prejudices and harmful practices relating to persons with disabilities, including those based on sex and age, in all areas of life;
- (c) To promote awareness of the capabilities and contributions of persons with disabilities.

2. Measures to this end include:

- a) Initiating and maintaining effective public awareness campaigns designed:
 - i. To nurture receptiveness to the rights of persons with disabilities;
 - ii. To promote positive perceptions and greater social awareness towards persons with disabilities;
 - iii. To promote recognition of the skills, merits and abilities of persons with disabilities, and of their contributions to the workplace and the labour market;
- b) Fostering at all levels of the education system, including in all children from an early age, an attitude of respect for the rights of persons with disabilities;
- c) Encouraging all organs of the media to portray persons with disabilities in a manner consistent with the purpose of the present Convention;
- d) Promoting awareness-training programmes regarding persons with disabilities and the rights of persons with disabilities.

SECTION 2

Please tick the boxes that apply. I am:

A person with autism	A parent/carer of a person with autism	Other e.g. relative	Organisation		
			Statutory	Voluntary	Private
		√	√		

My age group is:

Under 18	18-25	26-50	51-65	Over 65
				√

Please forward your response:

By e-mail to: autism.strategy@health-ni.gov.uk

By post to: Autism Strategy
Room D2:17
Castle Buildings Stormont Estate
Belfast
BT4 3SJ

Responses must be received no later than 8th October 2021.

Thank you for your comments.