



Department of
Health

An Roinn Sláinte

Mánnystrie O Poustie

www.health-ni.gov.uk

AUTISM INTERIM STRATEGY 2021-2022

CONSULTATIVE PROCESS Summary of Responses

FEBRUARY 2021

INTRODUCTION

The Autism Act (NI) 2011 places a statutory responsibility on the Department to prepare a cross-departmental autism strategy every seven years. The previous autism strategy 2013-2020 came to an end in December 2020. Whilst preparations had been underway to develop a fully co-produced autism strategy for implementation in 2021, the significant impact of the COVID-19 pandemic and the urgency placed upon the Department, and across all departments and the Health and Social Care sector to respond to escalating priorities resulted in these plans being paused.

However, mindful of the extensive targeted stakeholder engagement which had been undertaken throughout 2019 and early 2020 and the deployment of alternative forms of engagement, for example through digital platforms and the launch of a public questionnaire, the Minister for Health, Robin Swann MLA, approved the preparation of a high level interim autism strategy for publication in early 2021 that would bring together the outcomes of this work, with a commitment to develop a fully co-produced strategy later in 2021.

KEY PRIORITIES

The interim autism strategy has been developed based upon key priorities identified throughout targeted stakeholder engagement which included:

- Regional standardisation and equity of access to services across the regions;
- Early intervention and timely access to services;
- Greater involvement of autistic people, their families in the development of policy and services;
- Equity in provision and access to Adult Autism Services; including mental health services;
- Long term/whole life approach to transitions planning;
- Social inclusion and opportunity for autistic people and their families to socialise and integrate in the community;
- Greater awareness and understanding of the needs of people with autism across all sectors;
- More availability of short break services; and
- Wider provision of supported living.

These priorities were reinforced following an analysis of responses which were received through the issue of a public questionnaire. A summary of responses to this questionnaire can be viewed at **Annex B** of the Autism – Interim Strategy 2021-2022.

In addition to this a scoping exercise was conducted across all Government Departments to determine actions for inclusion, based upon the key priorities

identified. The actions are aligned to the NICS Outcomes Delivery Plan, keeping them at the core of government activity and will be collated to form an outcomes based monitoring framework to assess progress in implementation and the difference the actions are making to the lives of autistic people, their families and carers.

Further to this, the Department has in recent years commissioned the Health and Social Care Board (HSCB) to develop a *Health and Social Care: Emotional Health and Wellbeing Framework for Children and Young People* ('the Framework'). The development of this Framework has been informed by a review of children's autism services undertaken by the HSCB and the Public Health Agency (PHA) and, given the ongoing pressures on the Health and Social Care sector, the implementation plan emerging from this Framework will form the basis for Health sector actions. In recognition of the need for improved equity and provision of adult autism services, a similar review was due to commence in 2020, however this was postponed due to the Covid-19 pandemic but will be included as an action for the interim strategy.

STRATEGIC OUTCOMES

From the key priorities identified and the actions that have been contributed, three clear strategic outcomes were identified which will form the basis of the interim strategy throughout 2021 and 2022:

- 1. A healthy life with access to services on an equal and timely basis** which will provide improved pathways of care enabling timely access to early intervention and support which best meets emotional and wellbeing needs for individuals and families;
- 2. A life with opportunities to live as an active citizen** to support autistic people, their families and carers as they participate in all aspects of community and society through continued support in education and employment and as they transition through life stages; and
- 3. An independent life with greater understanding and choices** which will provide opportunity for autistic people, their families and carers to live safe and independent lives within our communities and have equal access to services where they are met with respect and understanding.

CONSULTATIVE APPROACH

Whilst a formal public consultation has not been conducted for the interim strategy, this will take place at a later date as part of the development of a fully co-produced strategy, a targeted consultative approach was undertaken to enable views to be expressed on the proposals which were set out as a direction of travel in the interim strategy.

The Department collated a response template, based upon the three strategic outcomes which would enable people to express their views and include any additional comments that they wished to convey, a copy of the response template is provided at **Annex A**. As part of this process respondents were also requested to include their vision for an autism strategy.

Prior to initiating a wider consultative approach, the Department had established a small Advisory Group comprised of professional colleagues representing social care, nursing and medical advisory services, statistical data and also parents and carers, for commentary and input on an initial draft of the strategy.

Following this, and in order to capture a comprehensive range of responses, the Department issued the interim strategy and response template to the five multi-agency autism forums which are hosted by regional Trusts and are comprised of clinicians, community and voluntary sector representatives, service users and Government/statutory bodies for example, education, employment and justice. The interim strategy was also forwarded to reference groups and parent/carer groups linked to the Trust in each respective area.

The questionnaire issued on 17 December 2020 with a closing date of 22 January 2021, this was subsequently extended until 29 January with the assurance that any late responses would be considered within the development of a fully co-produced strategy later in the year. All responses were treated as anonymous.

The Department offered to engage with any groups, in line with social distancing requirements and public health guidance, or respond to individuals should further discussion or information be required. The Department also presented the interim autism strategy to the Southern Trust, Northern Trust and Belfast Trust Forums who had meetings planned in January 2021.

The Department accepts that the timing of the launch of the interim strategy posed challenges for organisations and for respondents given the Christmas period. Due to the restricted timescales in place for development an easy read version was not available, the Department acknowledges that this presented difficulty for some respondents and this will be a consideration for future consultative processes.

RESPONSES RECIEVED

The Department received 28 responses on behalf of 40 people (some group responses were received).

A breakdown of respondents is provided in **Table 1**.

FINDINGS

Responses received from the consultative process have broadly reinforced views expressed in the public questionnaire which issued in the summer of 2020.

Whilst the introduction of an interim strategy has largely been positively accepted, 2 respondents suggested that the 2013-2020 autism strategy should be extended for a further year. However, given the changing landscape since the introduction of the previous strategy and the absence of an action plan since 2017, the Department considers this would not be an appropriate response at this time, but rather the interim strategy should be published to set a refreshed strategic direction of travel pending the development of a fully co-produced strategy later in 2021.

Where suggestions for amendments to terminology, phrasing or presentation of the strategy have been made, these have been addressed, this also included the provision of a shorter, summarised document. The Department has carried out an analysis of the responses to ensure that future actions reflect the suggestions which have been made.

A summary of responses is outlined in **Table 2**.

VISION

The Department also considered the themes emerging from suggestions provided in relation to a vision for a strategy and from this three key themes consistently emerged: people want to feel respected, they want others to listen to them and understand their needs and they want to be involved in decisions about them and advise on how their needs can be supported. Based upon this the vision created for the interim autism strategy will be ***'To respect, to listen, to involve.'***

TABLE 1**Breakdown analysis of Respondents**

Number of Respondents	Total number of Respondents	Respondent	
28 15 Individuals 13 Groups	40	Person with Autism	3
		Parent/Carer	14
		Other e.g. relative	2
		Health Sector	7
		Statutory Organisation	12
		Community/ Voluntary Organisation	5
		Private Organisation	3
Please note that some respondents registered under multiple categories			

TABLE 2

Summary of Responses

SUMMARY OF RESPONSES		
1.	Vision	Comments
	What is your vision for a revised strategy?	Whole life bespoke approach Pre and post diagnosis support and intervention Bespoke supported Living Training and awareness around employment Access to respite services Revised adult services Regional consistency Clear, measurable, achievable goals Stronger links between health and education Genuine involvement of autistic people Change in society Quality of prevalence data Co-production Timely and effective multi-agency working

2.	Key Priorities	Further Suggestions				
	<p>Do you agree with the key priorities (page 9) of the interim autism strategy?</p> <table border="1" data-bbox="264 501 629 619"> <tr> <td data-bbox="264 501 629 564">Yes</td> <td data-bbox="629 501 990 564">No</td> </tr> <tr> <td data-bbox="264 564 629 619">24</td> <td data-bbox="629 564 990 619">0</td> </tr> </table>	Yes	No	24	0	<p>Support and awareness for people with autism and their carers including community support</p> <p>Education and awareness for public services</p> <p>Respite for autistic people and their families and carers</p> <p>Life skills training</p> <p>Access to physical and psychological services</p> <p>Access to supported living</p> <p>Joined up approach across children to adult services</p> <p>Early intervention</p> <p>Investment to match demand</p> <p>Clear pathways</p> <p>One stop shop</p> <p>Independent scrutiny and monitoring</p> <p>Signposting for regional autism services</p>
Yes	No					
24	0					

3.	Do you agree with the Strategic Outcomes for the interim autism strategy?	Further Suggestions				
	<p>a) A healthy life with access to services on an equal and timely basis. (page 14)</p> <table border="1" data-bbox="273 459 987 582"> <tr> <td data-bbox="273 459 629 523">Yes</td> <td data-bbox="638 459 987 523">No</td> </tr> <tr> <td data-bbox="273 523 629 582">24</td> <td data-bbox="638 523 987 582">0</td> </tr> </table>	Yes	No	24	0	<p>Supported employment opportunities Access to specific and tailored support and services for all ages including physical and mental health support Training and support for carers and families including co-existing conditions Access and standardised services Respect for autistic people and their families Effective and timely diagnosis and intervention for all ages Education on relationships Respite services for autistic people, families and carers Autism awareness across schools with clear education pathways Increased funding to match need</p>
Yes	No					
24	0					

4.	Do you agree with the Strategic Outcomes for the interim autism strategy?	Further Suggestions				
	<p>b) A life with opportunities to live as an active citizen? (page 15)</p> <table border="1" data-bbox="264 459 987 582"> <tr> <td data-bbox="264 459 629 523">Yes</td> <td data-bbox="629 459 987 523">No</td> </tr> <tr> <td data-bbox="264 523 629 582">24</td> <td data-bbox="629 523 987 582">0</td> </tr> </table>	Yes	No	24	0	<p>Supported working opportunities Whole life specific support when required Training and awareness including education and employment sector Respecting the rights and humanity of autistic people People with autism and their carers involved in decision making Interdepartmental/multi agency approach Access to and investment in social activities/networking Greater communication between health and education Highlight strengths people with autism bring to workplaces Autism friendly communities including schools Signposting to regional services Access to supported living Support in higher and further education Wrap around care Outline what 'active citizenship' means</p>
Yes	No					
24	0					

5.	Do you agree with the Strategic Outcomes for the interim autism strategy?	Further Suggestions				
	<p>c) An independent life with greater understanding and choices? (page 16)</p> <table border="1" data-bbox="264 459 990 582"> <tr> <td data-bbox="264 459 627 523">Yes</td> <td data-bbox="627 459 990 523">No</td> </tr> <tr> <td data-bbox="264 523 627 582">24</td> <td data-bbox="627 523 990 582">0</td> </tr> </table>	Yes	No	24	0	<p>Training and awareness for public bodies Paid employment for people with autism Awareness, understanding and training in particular around health, education and employment Autism friendly environments Active and meaningful engagement with autistic people including in planning and implementation Access to residential breaks Access to independent living Timely diagnosis and assessments Support on relationships Accountability of strategy Public awareness campaign Services informed by and provided by autistic people Improved working between health and education Social inclusion and participation Greater investment in adult services Whole life approach</p>
Yes	No					
24	0					

6.	Additional Comments
	<p>Mental health resources and services must be prioritised and more accessible.</p> <p>Strategic linkages to other strategies, particularly mental health.</p> <p>Access to services without a diagnosis.</p> <p>Equity of access to assessment and diagnosis.</p> <p>Ownership, leadership and accountability from Department.</p> <p>Robust monitoring mechanisms for implementation of strategy.</p> <p>Appreciated use of language i.e. autistic person.</p> <p>Improved partnership between statutory and community and voluntary services required.</p> <p>Equal participation in society.</p> <p>Impact of COVID-19 on services and support.</p> <p>Specific Autism budget is needed.</p> <p>Fully co-produced strategy in 2021.</p> <p>Inclusion in NI Census 2021 positively received.</p> <p>Easy read versions must be made available.</p> <p>Independent evaluation of strategy should be carried out.</p> <p>Monitoring group should be established.</p> <p>Unrealistic outcomes for 2 year period.</p> <p>Extend current strategy rather than introduce interim autism strategy.</p>

AUTISM INTERIM STRATEGY 2021-2022

RESPONSE TEMPLATE

Following the introduction of the Autism Act (NI) 2011 the first autism strategy, 2013-2020, was published in 2014. The strategy set 11 key themes aimed at supporting people with autism to better exercise their rights, choices and life opportunities.

The strategy has now come to an end and whilst preparations had been underway to develop a fully co-produced autism strategy for implementation in 2021, these plans were significantly restrained as a result of the Covid-19 pandemic.

Throughout this period we have continued to keep in contact with all stakeholders and have sought alternative methods of engaging with the community and voluntary sector and with autistic people, their families and carers; for example, through meetings held on digital platforms and the issue of a public questionnaire.

Mindful of the challenges experienced by individuals and families as a result of the pandemic, the Minister for Health, Robin Swann MLA, has agreed that the outcomes of this work, and of extensive stakeholder engagement undertaken by the Department of Health throughout 2019 and 2020, could be brought together in a high level interim autism strategy for publication early in 2021, which would ultimately inform the development of a fully co-produced autism strategy later in 2021 to ensure that the implementation of actions will not be delayed at a time when need has never been greater.

Throughout our stakeholder engagement there has been a very clear message coming across from families and individuals about the key areas that should be addressed through a revised autism strategy and we have tried to capture these within three strategic outcomes listed within the strategy:

- 4. A healthy life with access to services on an equal and timely basis** which will provide improved pathways of care enabling timely access to early intervention and support which best meets emotional and wellbeing needs for individuals and families;
- 5. A life with opportunities to live as an active citizen** to support autistic people, their families and carers as they participate in all aspects of community and society through continued support in education and employment and as they transition through life stages; and
- 6. An independent life with greater understanding and choices** which will provide opportunity for autistic people, their families and carers to live safe and independent lives within our communities and have equal access to services where they are met with respect and understanding.

We want to hear your thoughts and views about the proposals set out in the interim autism strategy and have shared a draft copy inviting you to send your comments to us in the attached response sheet.

Please answer as many or as few questions as you wish, alternatively you can answer the 'Additional Comments' section giving us your thoughts on the proposed interim autism strategy at the end of the response form.

We look forward to hearing from you.

Please send your response **by Friday 22nd January 2021.**

**LEARNING DISABILITY UNIT
DEPARTMENT OF HEALTH**

Email: Autism.Strategy@health-ni.gov.uk

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 response to this document.

Thank you.

AUTISM INTERIM STRATEGY 2021-2022

We want to hear your views.

1 What is your vision for a revised autism strategy?

2 Do you agree with the key priorities (page 9) of the interim autism strategy?

Yes No

Are there any other priorities for consideration?

3

Do you agree with the Strategic Outcomes for the interim autism strategy?

a) A healthy life with access to services on an equal and timely basis. (page 14)

Yes

No

Is there anything further you would like to suggest?

b) A life with opportunities to live as an active citizen? (page 15)

Yes

No

Is there anything further you would like to suggest?

	c) An independent life with greater understanding and choices? (page 16)
	Yes <input type="checkbox"/> No <input type="checkbox"/>
	Is there anything further you would like to suggest?
4	Additional Comments
	Do you have any additional comments you would like to make?

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			
			Health Sector	Statutory	Voluntary	Private

Please e-mail your response to Autism.Strategy@health-ni.gov.uk no later than Friday 22nd January 2021.

Thank you for your comments.